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Biosocial Journeys:  
Care and Community in Experiences of  
Body-Focused Repetitive Behaviours

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Bridget Bradley

PhD Social Anthropology  
The University of Edinburgh  
2019



## Declaration

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I declare that, except where otherwise indicated, this thesis is entirely my own work, and that no part of it has been submitted for any other degree or professional qualification.

Bridget Bradley

June 2019



For Matt, with love



## Abstract

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This thesis follows the emergence of a biosocial community and shows the importance of social relations for British and American people living with body-focused repetitive behaviours (BFRBs). It is based on sixteen months of ethnographic fieldwork in multiple sites across the UK and the US. I describe the experiences of women, men, and young people living with hair pulling (trichotillomania) and skin picking (dermatillomania), as well as their loved ones, health professionals, researchers and hairdressers working in the field of BFRBs. I present an in-depth view of what it is like to live with BFRBs, and the stigma and risk involved in the process of concealing and revealing to others. Exploring the complexities of how BFRBs are embodied, I show the shame and confusion that people feel towards their own bodies, triggering negative perceptions of the self. The suffering caused by BFRBs is reflected in families, with parents sharing feelings of loss, grief and frustration with their BFRB children. I expand on kinship theories to unpack these experiences through the concept of intersubjectivity, illustrating how parents are both connected and separated by their shared experiences with children. From these domestic challenges stem care practices that blur the boundaries between love and harm. Within the wider contexts of care, health professionals are described as unsupportive and uninformed, and people rarely receive effective support from the medical sphere. But despite the disappointments in medical care, diagnosis still has a value, and the journey that people living with BFRBs go through towards biosociality is dependent on the medical label. People therefore transition from isolated shame to connecting with others who share their embodied experience, forming relationships that are comparable to kinship ties. I argue that the process of finding and forming the biosocial BFRB community, allows people to overcome long-term feelings of shame, and leads to alternative notions of recovery. But biosociality is complex; it involves conflict, issues of inclusion, and ongoing work in order to be sustained. Due to the limits of biosociality, some people in the BFRB community are inspired towards *biosolidarity*; where BFRB experiences are turned into acts of advocacy that raise awareness and make these disorders visible



in new ways. This thesis involves combined ethnographic and auto-ethnographic perspectives, and hopes to bring BFRB experiences to the attention of scholars, professionals and lay people living and working with mental disorders.

## Lay Summary

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This research shows the importance of social relationships for British and American people living with body-focused repetitive behaviours. It is based on sixteen months of in-depth fieldwork in multiple sites across the United Kingdom and the United States. It includes the experiences of women, men, and young people living with hair pulling (trichotillomania) and skin picking (dermatillomania), as well as their loved ones, health professionals, researchers and hairdressers working in the field of BFRBs. I explore the moment that people living with hair pulling and skin picking “find out the name” for their behaviour, and how this often leads them to find one another online or in-person. I show how this moment can lead to new ways of seeing BFRBs, for those who come together in support groups and conferences, but also for the public through the media. By mapping this process of coming together, I argue that the strong connections felt between sufferers have the ability to overcome long-term feelings of stigma and shame associated with BFRBs, and can bring people closer to recovery and self-acceptance. I also show how families struggle to deal with the effects of BFRBs in their children, highlighting the strain on parents and loved ones to fully understand the way BFRBs *feel*. From this, I expand our understanding of how families cope with the effects of a complex mental disorder. By examining other forms of care, I show how health professionals are frequently described as unsupportive and uninformed, and how people struggle to find effective support for BFRBs. Alongside my research participants, I also present my own personal perspective on living with trichotillomania, which has influenced my ongoing advocacy work within this community. Through this thesis, I hope to bring BFRB experiences to the attention of scholars, professionals and lay people living and working with mental disorders.



## Acknowledgements

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## List of Figures

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Figure 1: Advertisement for Perfectil .....	39
Figure 2: Beautiful Bald Barbie Campaign .....	145
Figure 3: Photographs of trichotillomania in The Mirror .....	146
Figure 4: Photographs of trichotillomania in The Daily Mail .....	146
Figure 5: Photographs of trichotillomania in The Sun .....	147
Figure 6: African American women attending the TLC Conference in 2018 .....	155
Figure 7: Beverley's Salon Waiting Area .....	157
Figure 8: Lou: "Conditions like trichotillomania aren't talked about enough" .....	185
Figure 9: "Pouring Mountains" by Liz Atkin.....	194
Figure 10: "Compulsive Charcoal" by Liz Atkin .....	195
Figure 11: Milcho's .....	202
Figure 12: "Resilience" by Liz Atkin, 2016 .....	209
Figure 13: "They Come Not As Single Sparrows" by Liz Atkin, 2011.....	209
Figure 14: "Blue" by Liz Atkin, 2013.....	210
Figure 15: "Acrylic: Los Angeles Residency" by Liz Atkin, 2008.....	210
Figure 16: Tiffany and I at the TLC conference 2015 .....	216
Figure 17: Tiffany and I at the TLC conference 2018 .....	217
Figure 18: TLC Logo 1993-2016 .....	228
Figure 19: TLC Logo from 2016 .....	228
Figure 20: Zoe's Instagram post, April 2016.....	230





## List of Abbreviations and Acronyms

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APA	American Psychiatric Association
BFRB	Body-Focused Repetitive Behaviour
BPM	BFRB Precision Medicine Initiative
BTC	Behavior Therapy Center
CBT	Cognitive Behavioural Therapy
CSP	Compulsive Skin Picking
Derma	Dermatillomania
DSM	Diagnostic and Statistical Manual of Mental Disorders
ICD	International Statistical Classification of Diseases and Related Health Problems
N-ac	N-acetylcysteine
OCD	Obsessive Compulsive Disorder
SAB	Scientific Advisory Board
TLC	The TLC Foundation for Body-Focused Repetitive Behaviors (previously the Trichotillomania Learning Center)
Trich	Trichotillomania
TTM	Trichotillomania



# Contents

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Abstract .....	7
Lay Summary .....	9
Acknowledgements .....	11
List of Figures.....	15
List of Abbreviations and Acronyms .....	17
Introduction: Welcome to the Family.....	23
Making BFRBs Visible.....	28
A Family of Disorders: A Brief History of BFRBs .....	30
Literature Review .....	34
Understanding the Body in BFRBs .....	34
Diagnosis and Medicalisation .....	44
From Biosociality to Biosolidarity .....	48
Kinship and Care .....	51
Methods .....	55
Demographics of the BFRB Community .....	55
Disentangling the Field .....	57
“Science and Storytelling”: The Anthropological Method.....	63
Ethical Considerations .....	65
Overview: Unravelling a Thesis .....	69
Ethnography as Biosolidarity .....	72
Chapter 1: “Disorders of Hiding”: Concealing the BFRB Body .....	75
Techniques of Concealment .....	77
Stigma and Risk of BFRB Bodies .....	82
Concealing Over Time.....	88
Embodied Shame.....	93
“A zoned-out sense of calm” .....	96
“I feel like I need to go to rehab” .....	99
Friend and Enemy, Pleasure and Disgust .....	102
Time for Acceptance.....	105
Conclusion .....	107

Chapter 2: Kinship Relations: Care, Harm and Intersubjectivity .....	109
Mixed Emotions for Parents .....	111
Boundaries Between Care and Harm .....	117
Tough Love.....	121
The Embodied Risk of BFRB Parents.....	125
“Be your own mother”: Reproducing Care .....	131
Conclusion .....	133
Chapter 3: BFRB Visibility: Empowerment and Risk.....	137
Visibility and Awareness .....	138
The Hair Pulling Spectacle .....	140
“Girls on the Pull” .....	142
Beautiful Bald Barbie .....	144
“Baldness can be attractive in men” .....	150
“Black Girls with BFRBs” .....	152
Beverley and the Angels .....	156
More Than Hair.....	165
Conclusion .....	168
Chapter 4: Building a Community: Medicalisation and Biosolidarity .....	171
“You are not alone” .....	173
Meaningful Medicalisation .....	176
“Have you tried sitting on your hands?” .....	180
Becoming Biosocial .....	183
Beyond Biosociality.....	186
The Circle of Biosolidarity .....	191
Conclusion .....	198
Chapter 5: Love and Recovery in the TLC Family .....	201
Self-Esteem and Self-Care .....	201
From Trigger to Tool: Technologies of Care .....	206
From Hiding to Healing: Biosociality as Recovery .....	215
Conflicts of Care.....	221
Care or Cure? .....	226
Conclusion .....	233

Conclusion: “We need to make <i>noise!</i> ” .....	237
Thesis Overview.....	240
Acts of Biosolidarity: Measuring Impact .....	244
Bibliography.....	247



## Introduction

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### Welcome to the Family

My host mother, Dawn,<sup>1</sup> told me that the cherry blossoms must have been waiting for me, as they came into bloom about a week later than expected, coinciding with my arrival in Washington, DC. The spring sunshine was a welcome change from the harsh Scottish weather, and I enjoyed a short burst of it before taking the car ride to the Marriott Hotel in Arlington. Dawn insisted on driving me, and I was thankful for the way her small-talk diverted my thoughts away from my nerves. We parked at the hotel entrance, and Dawn wished me luck before she drove off.

April 2015 was my first time in Washington, DC, and I had come to attend a conference to secure approval for my upcoming fieldwork. Jude, a friend and PhD researcher from Glasgow University, had told me about an organisation that ran conferences each year for families and professionals dealing with BFRBs. Then called the Trichotillomania Learning Center (TLC), but recently renamed the TLC Foundation for Body-Focused Repetitive Behaviors, “TLC” are a non-profit organisation based in the United States, but who provide resources and research for people worldwide. During my master’s a few years earlier, Jude had helped me to enter the BFRB world, adding me to various Facebook groups which allowed me to get a view into this vast community online. Beyond the online groups, I had only met a handful of people who lived with hair pulling or skin picking in person.

I was drastically unprepared for what this conference would involve. On arrival, the hotel lobby was surprisingly quiet, as I looked for signs of other attendees. I spotted a young woman wearing a headscarf, carrying a lime green tote bag with TLC’s logo and I realised I was in the right place. I sat for a moment, and soon noticed more people with green bags travelling up and down the wide winding staircase. I followed them

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<sup>1</sup> The majority of people in this thesis have been anonymised.



slowly up the stairs. At the top, just a few metres away was Jude, seated at the welcome desk. She was surrounded by other volunteers, who smiled widely at each new attendee, handing them their tote bag and a lanyard. I approached the table sheepishly, and Jude spotted me, jumping up from the table with excitement. She hugged me warmly and instantly introduced me to the people around her, explaining I had come “all the way from Scotland”. Very quickly Jude’s attention was taken back to her volunteering duties, and I was shuffled down the line to receive my tote bag and name badge. The lanyards were colour-coded, green if you consented to being photographed, and black if not. I took my green lanyard and my name badge which was decorated with a bright blue and gold ribbon that said “First Time Attendee”.

Walking towards the ballroom, I passed tables selling fidget toys and books; representatives from various OCD and anxiety organisations; and different stands promoting beauty products and wigs. Turning a corner, I caught sight of the main ballroom, filled with large tables and people seated, standing, hugging, laughing, all seemingly known to one another. There must have been a few hundred people, with many more milling around in the corridors and downstairs. There were men and women, boys and girls, children and parents. What struck me instantly was the number of young people, many who looked not yet in their teens, some with family members, but others walking in groups of other children. They wore colourful headbands and scarves, wigs and shaved heads, some faces painted with make-up and others make-up free, concealing or revealing their lack of eyebrows and lashes. I didn’t feel ready to go further into the ballroom at that moment, and the sense of overwhelm led me out to the open balcony for fresh air.

I stood there looking out at the industrial environment around the hotel, the late afternoon April sun hitting the concrete and bouncing off cars. I thought about my parents, and my eyes filled with tears. I considered how different things might have been for us as a family if they had been able to attend an event like this. I felt completely naïve, having not anticipated any of these feelings. I had spent the

preceding months concerning myself with the logistics of fieldwork, attempting to build my confidence as a researcher in order to convince TLC to take me seriously on my arrival, and I had not considered for a moment that I might see my younger self in that room. I was prevented from pondering too long, as a tall man with curly dark hair and thick-rimmed glasses walked out onto the balcony. He wandered aimlessly for a moment, looking for a place to stand. He was dressed fairly smartly, wearing a short sleeved checked shirt, a leather satchel hanging casually from his shoulder. He didn't quite smile, and certainly didn't appear to invite any interaction with me, but at that moment I remembered why I was there and that I was an anthropologist. Saying hello, I asked if he was there as a parent or a professional. Slowly and quietly he told me that he was actually here for himself, and I noticed the First Time Attendee ribbon attached to his name badge: "Jack". As I was also attending the conference alone, we shared some of our reasons for and anxieties around being there. After building up some courage, Jack and I re-entered the ballroom, and spurred on by our new friendship, we stuck together that weekend and attended most sessions together. He referred to me as his first "trich<sup>2</sup> friend", as I was officially the first person he had met who also had trichotillomania.

It wasn't until the end of the conference weekend that I managed to approach TLC's Managing Director, Jennifer Raikes, to speak to her about my research. For her, there was no question about TLC's involvement in my work, and she emphatically agreed for that I could include them in my research. I thanked her and told her how important this weekend had been for me personally as well as professionally. I said: "We just have *nothing* like this in the UK, there's *nothing*." And she replied: "Well, it's up to you now, people like you and Jude and Dhaya. You're part of the family now". I realised then that my role in this community would reach far beyond that of a researcher. By welcoming me into this "family", I was also being presented with a set of responsibilities. This sense of duty, instilled even before my fieldwork officially began, set the scene for what was to come, and has shaped the relationships I went on to

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<sup>2</sup> "Trich" is the one of the nick-names for trichotillomania.

foster with Dhaya in particular, and our subsequent decision to collaborate and set up the UK's first ever support group for people living with BFRBs. It is through my personal experiences that this thesis, and its arguments came into being, and through this research that I both observed and shaped the emergence of the BFRB community in the UK.

This thesis describes the way a community becomes visible, and shows the deeply relational aspects of community-forming; across borders, and through shared embodied experience. Within this process, the moment of "diagnosis" holds great importance in people's lives. I use the language of diagnosis to describe the moment people "find out the name", which was described to me by all of my interlocutors. This rarely involves being diagnosed by a professional, but instead self-diagnosing usually through internet searches. The overriding emphasis on the label of "trichotillomania" or "dermatillomania" legitimates the confusing embodied experiences that people have and offers an opportunity to become part of a biosocial group. The thesis will map this journey, and shows the ways that biosociality is connected to visibility, bringing the BFRB community into view in multiple ways. However, the way that a community becomes visible, is dependent on the media and other powerful figures that influence the images present in public culture. As we will see, the way trichotillomania is presented in the press excludes certain types of people from becoming visible and threatens their access to biosocial networks. So while this thesis emphasises the value of biosociality, it also reveals the challenges and tensions of this process, highlighting the vulnerability of biosocial communities which involve maintenance and collective effort in order to be sustained.

The family metaphor runs throughout this thesis, and in the coming chapters I will show how biosociality – as shared embodied experience - can be understood through the framework of kinship. Anthropologists are often welcomed into families during the fieldwork process, and with that inclusion comes many of the aspects that we might attribute to kinship: intimacy, belonging, emotion, conflict, obligation and care - all of

which will be addressed in this thesis. I follow the ways that people come together, in searching for and making a biosocial group, and show how this biosocial group comes to be considered a family. For some people, becoming part of this biosocial group, through either attending a TLC conference, joining a support group in-person or online - inspired them towards *action*. This thesis then explores the ways that biosociality can lead to productive forms of advocacy, which I call biosolidarity. As I will show, these acts of biosolidarity offer new ways of seeing BFRBs in public culture, that resist or challenge existing representations in the media, and contradict biomedical frameworks of care. Ultimately, the effects of biosociality and biosolidarity have the potential to change the way people view the self, and care for the self. The impact of biosociality inspires people towards advocacy work on behalf of the BFRB community. Importantly, this biosolidarity is reproductive and with increased visibility of the BFRB individual, comes the opportunity for more biosocial connections to be made. I have called this process the circle of biosolidarity.

In this introduction I will firstly offer some context to body-focused repetitive behaviours. As this thesis will explain, BFRBs are not well-known in public culture. They are also largely absent from academic work, with research limited to the psy-sciences, much of which is being driven by TLC and their Scientific Advisory Board, and therefore based in the United States. I begin by summarising the main findings from this body of research, both to introduce the reader to the epidemiological view of BFRBs, but also to frame these conditions within the field of biomedicine. I will also show how this thesis sits alongside the existing research. I follow by outlining my contribution to anthropological and sociological theories in a literature review that contains a summary of my main themes. Here I will describe the way my analysis has been shaped by scholars' concepts of the body, including a discussion on hair and skin, gender and race, stigma and the self. My literature review moves on to discuss medicalisation theories on diagnosis and labelling; as well as anthropological investigations on care, kinship and biosociality. My methodology section will then give a detailed overview of the fieldwork process, and the various sites and people that were included in its scope,

as well as offer context to the BFRB community. I then present a chapter overview, setting the scene for what is to come.

It should be noted that BFRBs do not fit easily into one box. As this thesis will show, they are complex disorders that defy simple classification and confuse peoples' notions of the self, mind and body. Through the work of analysing BFRB experiences, my attempts to apply an overarching theme or theoretical framework did not seem to fit. Nor did it fit with what BFRBs stand for or represent how they are experienced. As a result, this thesis crosses conceptual boundaries between a number of themes, which may appear too broad, or at times contradictory. To my readers, I encourage you to trust me; BFRBs are at the same time confusing and frustrating, as they are weird and wonderful – this is why they are interesting.

### **Making BFRBs Visible**

This thesis and related publications (Bradley & Ecks 2018) are the first accounts of trichotillomania or skin picking to feature within the social sciences. One of the challenges of being the first, is that there is a paucity of literature to draw on or compare to. For this reason, I attempt to outline in this introduction some of the existing background literature to allow the reader enough context of BFRBs before moving on to my own research into these behaviours. As we will see, BFRBs are complicated embodied disorders, and as such the more we begin to unravel them, the more questions arise. Therefore, there are some questions that this thesis will not address fully. One particular discussion that I will not dwell on, is the question of what BFRBs *are*. While I do discuss current diagnostic classifications, and the importance of labels, I do not delve further into the question of whether or not BFRBs are indeed a pathology, or ideas about the social constructions of illness. For reasons that to question the pathological nature of BFRBs would undermine the legitimacy and meaning that diagnosis offered people. As we will see, the medicalisation of BFRBs moves people from “abnormal” to pathological in important ways, creating a sense of normalcy and belonging, and it is to this aspect that I give focus. One reason I choose

not to engage in this discussion is to avoid any confusion over whether BFRBs are considered “real” mental disorders”. Like Hacking (1998) has shown in the case of multiple personality disorder, and Ware (1992) with chronic-fatigue syndrome, these questions stem from stigmatisation from health professionals who question the authenticity of patient suffering – which I do not wish to reinforce. In some aspects, the debate around *what BFRBs are* is influenced by the labels given to these disorders, and this aspect I will address when I describe the official classifications of hair pulling and skin picking in psychiatric domains as well as everyday perceptions of what they are by medical professionals (self-harm, habits, nervous behaviours, OCD etc.). I will outline the ways that these confusing and often conflicting views on what BFRBs are transcends into everyday life and can complicate family life when parents and loved ones attempt to deal with family members who are struggling with BFRBs. However, I do not attempt to give my opinion on what I believe BFRBs are and why, but instead choose my descriptive language in line with my interlocutors, who used a number of different words to describe their hair pulling and skin picking (behaviour, disorder, condition, illness), which I will use interchangeably.

In addition, this thesis does not attempt to address the question of how BFRBs are *caused*. This conversation is rife in the BFRB community, but as yet there remains limited understanding in the biomedical research (Murphy & Flessner 2015), although efforts to uncover their origins are ongoing. The question of how BFRBs are caused is somewhat connected to the question of what BFRBs are, as Hacking (1998) has shown. In his book “Rewriting the Soul”, Hacking challenges the question of whether multiple personality disorder is “real” and says, “Is multiple personality a real disorder as opposed to a product of social circumstances, a culturally permissible way to express distress or unhappiness?” (1998: 13). Hacking says that we should reject this question, as it implies a contrast between “real” disorders and illness being a product of social circumstances. He argues that just because a mental disorder is made visible through certain social circumstances does not mean that it is “manufactured, artificial, or in any other way not real” (1998: 12). In the context of BFRBs, there has been a similar

debate throughout the years, with earlier studies describing hair pulling and other “nervous habits” as a reaction to “extreme” events such as physical injury or psychological trauma (Azrin & Nunn 1973: 620). Recent researchers have discounted the social and environmental causes of hair pulling and skin picking which reflects a more general shift away from psychoanalytic understandings of mental illness. As Penzel has argued about trichotillomania, “Psychoanalytic theory encouraged this type of thinking by placing blame largely on parenting and development. There is not a psychological problem at the bottom of it all” (Penzel 2003: 226). For my interlocutors, the cause of their BFRB was often questioned in relation to family history. Some people told me they thought their hair pulling began following the divorce of their parents, others did connect hair pulling to experiences of trauma in earlier life. The question of “where did this come from?” and “why me?” were often asked, especially for those who considered themselves to have “normal” and “happy” childhoods. So while American researchers discount the importance of personal histories in the causation of BFRBs, the importance of these questions to people themselves may still be valuable and therefore should not be discredited. In this thesis, I choose not to engage in this debate directly, but in Chapter Two I do highlight the importance of family in terms of embodied risk associated with BFRBs. This is pertinent to ongoing debates in the BFRB community as the shift away from psychoanalysis towards understanding BFRBs as neurobiological conditions that may have a genetic basis (Penzel 2003: 226). In my conclusion, I will revisit this debate to discuss how the role of genetics affects the possibilities of finding a cure in the BFRB community and the impact of these discussions on people who live with these disorders.

### **A Family of Disorders: A Brief History of BFRBs**

Medical knowledge on BFRBs has grown in recent years, and has been largely influenced by the grassroots demands spurred on by TLC as a “patient”<sup>3</sup>-led

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<sup>3</sup> In this thesis I refrain from using the word “patient” as it was not used by my interlocutors. Despite its negative connotations, I sometimes use “sufferer”, although I rarely adopt the preferred terms noted by some clinicians; “client” or “consumer”.

organisation. TLC's ongoing collaboration with clinicians and researchers has helped to bring these disorders into focus, and created ways to fund projects that were otherwise refused funding. At the TLC conference in 2016, the organisation's Chair of the Board explained that the majority of funding for BFRBs had come both from researchers' own pockets, and the "goodness of their hearts"; he added: "our research is based on love... we're doing this because we care and we love this community". Below I will outline some of the key findings that this research presents, to give an overview of how BFRBs are viewed in the medical sphere. In the wider thesis I will expand on the view of medical professionals by presenting conversations I had with many of these researchers. Beyond the United States, there is an increasing number of BFRB studies emerging from all over the world, including India (Mishra, Kelkar & Kumar 2018), Pakistan (Khan et al. 2018), Australia (Slikboer et al. 2018), Brazil (Appak et al 2018), Poland (Prochwicz & Kałużna-Wielobób 2018) and Romania (Rosu et al. 2018), to name just a few. We can tell by the diversity of these studies that interest in BFRBs is on the rise, and that these conditions do not only affect Euro-American populations.

The name "trichotillomania" was first coined by the French dermatologist Hallopeau in 1889 to describe the abnormal pulling out of body hair by a young man (Stein & Christenson 1999: 2). There is evidence of trichotillomania in the history of medicine, with hair pulling and skin picking appearing even in the Hippocratic corpus dating back to 400BC (Kim 2014). Broader awareness of the pathophysiology and the epidemiology of trichotillomania is relatively recent, and has increased following its introduction into the revised third edition of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association 1987 - hereafter APA and DSM). Despite similar historical accounts of skin picking, the psychiatric recognition of dermatillomania has been surprisingly slow in comparison to trichotillomania, entering into the DSM only in its most recent edition (APA 2013). In Chapter Four, I will describe the ways these classifications have changed over time, and the effects of these changes on the people who live with them; but for now it is important to mention that



the term BFRB is not yet recognised by the DSM, although my interlocutors used it widely. According to the DSM, hair pulling and skin picking currently belong within the group of “obsessive-compulsive and related disorders”, having been moved from “impulse-control disorder not elsewhere classified” featured in an earlier version (APA 1987). Due to the many names that these behaviours take on, in this thesis I refer to hair pulling as “hair pulling disorder”, “compulsive hair pulling”, “trichotillomania”, “trich” or “TTM” depending on how my informants used these names. While the DSM uses “excoriation disorder” to refer to skin picking, I rarely heard this being used by sufferers themselves (although it was used by clinicians), and so I use the preferred terms of “dermatillomania”, “derma”, “compulsive skin picking” and “CSP”. TLC’s recent push to establish the new label of “body-focused repetitive behaviours” came from their dissatisfaction in being grouped together under “impulse-control disorder not elsewhere classified” alongside kleptomania and compulsive gambling (Stein et al. 2010). Some progress was made in the DSM V with trichotillomania and excoriation disorder being formed into a new category of “obsessive-compulsive and related disorders” (APA 2013). Since then, researchers associated with TLC advocated for the use of the new classification of BFRB in the ICD 11 (Grant & Stein 2014), and were successful with its inclusion in June 2018 (World Health Organization 2018). The frequent re-classifying of trichotillomania has been described as one of the many “disagreements” on BFRBs among researchers (Rogers 2014), but it also confirms the idea that hair pulling is a heterogeneous condition, which is complex and often defies straightforward classification (Christenson & Mansueto 1999). The heterogeneous experiences of BFRBs, and the subtle differences from person to person, trouble not only the existing diagnostic criteria but also the choices for therapeutic intervention (Duke et al. 2010, Stein et al. 2010). BFRBs are a prime example of how psychiatric classifications are always “in motion” (Hacking 2007: 640), but they also emphasise the role of patient advocacy in their ongoing motion and formation; an aspect that is becoming increasingly recognised within the medical sphere (Stein & Phillips 2013).

The prevalence of BFRBs is difficult to measure due to the secrecy of its sufferers,

making it difficult to gather accurate demographic data. An earlier study suggests that 4% of the United States population suffer from trichotillomania (Azrin and Nunn 1977), disproving the previous opinion changing the previous notion that it was a “rare” condition (Christenson & Mansueto 1999). An updated figure of 4.4% was suggested by Grant et al. in 2005, other numbers have varied from somewhere between 0.6% and 3.4% (Rogers 2014). More recently, TLC claims that “1 in 25” people worldwide are likely to suffer from a type of body-focused repetitive behaviour to the extent that it interferes in daily functioning (TLC Foundation for BFRBs Website). It is possible that skin picking is more prevalent in the general population, although much less is known about its lived experiences (Keuthen et al. 2010).

Trichotillomania seems mostly to affect women, and the age onset has been averaged at thirteen-years-old (Christensen 1995). Childhood-onset hair pulling (under age five) is considered easier to treat and less likely to develop into adult trichotillomania - the reasons for which are unclear (Swedo & Leonard 1992). As I have mentioned, there have been no solid conclusions surrounding the origin of BFRBs, but it has been suggested that they could begin in any context of “change” such as childhood illness, death in the family, moving house, separation from friends, school tensions, parental divorce, birth of a sibling or other traumatic events (Christenson & Mansueto 1999). Authors have noted the differences in styles of pulling and picking, separated into “automatic” versus “focused”: automatic being done in semi or part consciousness, usually when doing another task; focused being when the pulling or picking is the only focus, and there is often a build-up of tension beforehand (Christenson & Mansueto 1999). Researchers have listed the different areas of the body that hair pulling can target, and described the various “rituals” that accompany different pulling routines. And they have noted the pleasure associated with hair pulling, as well as the absence of pain (Mansueto 1990). Despite this, others have referred to trichotillomania as self-injurious behaviour (Primeau & Fontaine 1987) and suggested it should be included in the self-harm continuum (Stanley et al. 1992), although this recommendation has been challenged by TLC. Other conflicts in the literature circulate around treatments, with the treatment of choice being cognitive behavioural therapy and habit reversal

training (Rogers 2014). Studies in psychiatry and psychology discuss the presence of embarrassment and shame, as well as efforts to conceal the behaviours (Chamberlain et al. 2007, Swedo & Rapoport 1991). The secrecy of trichotillomania has been described as a characteristic of the condition, suggesting similarities to eating disorders (Swedo & Rapoport 1991), and yet the in-depth lived experiences of shame and concealment in wider BFRB research have not been explored.

The recurring theme that is mentioned in the majority of biomedical literature on trichotillomania is treatment. As it stands, there is currently no cure and even recent developments in research fail to achieve any consistent form of treatment which has been successful for everyone (Rogers 2014). While attempts have been made to control hair pulling behaviour by medication and therapies, so far the most successful form of treatment in reducing, but not stopping, hair pulling behaviour is cognitive behavioural therapy (Christenson & Mansueto 1999, Rogers 2014). With regards to treatment, the current literature has failed to consider the value of management rather than treatment.

## ~ Literature Review ~

### **Understanding the Body in BFRBs**

The theoretical framework of this thesis speaks to many themes relevant to medical and social anthropology. But by offering an in-depth view into the lived experience of BFRBs, this thesis also fills a gap in the existing research on BFRBs and as such, is an important contribution to psychology and psychiatry. Current research being conducted on hair pulling and skin picking is often disconnected from the social influences on BFRBs; reducing treatment options to neurological and cognitive interventions aimed at the individual. By focussing on the embodiment of BFRBs, this thesis speaks to ongoing discussions in the sociology and anthropology of health and illness, arguing that there are multiple ways of experiencing illness through bodies. These debates have offered other sciences the opportunity to broaden our

understanding of how people make sense of illness and disease in nuanced ways. In this section I will attempt to summarise the vast literature on embodiment, hair, skin, and stigma.

The bulk of the psychiatric literature treats hair pulling and skin picking as compulsive behaviours located in individual minds and genes, with a specific way of understanding the BFRB body. Bodies are often negatively described in relation to the “physical damage” caused by BFRBs, mostly hair loss and skin lesions, but also repetitive strain, and gastric blockages that occur when people ingest the hair after pulling it (Penzel 2003: 5). While the physical result of hair pulling and skin picking were usually perceived as negative by my interlocutors as well, the *act* of pulling and picking was more often a source of pleasure. I will unpack the embodied experiences in Chapter One, using comparisons with self-injury (Chandler 2016) and eating disorders (Warin 2010) to show that seemingly “harmful” behaviours can involve aspects of pleasure rather than pain.

Psy-literature on BFRBs describes the body in terms of different “sites” where pulling and picking take place, categorising the different body parts that are “targeted”; scalp, eyebrows, eyelashes, pubic hair etc. The body is seen as a thing that is *acted upon*, and not an “experiencing agent” in itself (Csordas 1994: 2). As such, an holistic and phenomenological approach to BFRBs has yet to capture the way that bodies and selves interact, and are experienced together. My interlocutors importantly talked about the body as having agency, which was often “out of control”. This was described to me in terms of “muscle memory” by Liz, a London artist who has picked her skin for nearly thirty years. She said: “I didn’t teach my body to do this, it’s thoughtless... my brain is telling my body what to do and how to move”. In other conversations with Liz, she described the way that her hands knew which part of her body to touch to find something to pick, and they would often move subconsciously, even causing her to be able to pick in her sleep. Another woman told me, “it’s like my hand and arm have a life of their own”. Following the work of Chandler (2013), BFRBs, like self-injury,

simultaneously challenge and reinforce Cartesian assumptions of body / mind duality, reinforcing the idea that there are multiple ways of experiencing illness through bodies. In Chapter One I will unpack this relationship between the mind and the body, connecting with ongoing debates within anthropology (Ecks 2009, Lock & Farquhar 2007, Scheper-Hughes & Lock 1987).

Thinking about the way that BFRB bodies move is reminiscent of Wool's (2015) work, which uses the idea of movement to convey the ways bodies of soldiers living with PTSD are changed after war. In her ethnography of soldiers in the United States she describes how certain experiences of war change the way the body feels, and alters perception in terms of heightened sensory awareness, and the increased understanding of risks in different environments. For people living with BFRBs, embodiment is not exactly the same, as the urge to pull hair and pick skin is not necessarily linked to trauma, although behaviours can be triggered by moments of stress or anxiety. But although BFRBs are not exactly brought on by past memories, the way bodies move *over time* reinforces the repetitive urges that people experience with hair pulling and skin picking, and shapes the way people *see themselves*. In Chapter One I will describe the relationship between movement and self-perception.

The repetitive nature of BFRBs that forms intense habits over time, increasing the control that the mind has over the body, which was described to me frequently through the language of addiction. Describing the strength of urges to pull her hair out, Dhaya said: "I *feel* like I'm a drug addict. I *feel* like I need to go to rehab". This was the same for other people I spoke to, and caused them to dismiss the idea that hair pulling and skin picking were simply "habits". Instead they described the building urges that increased in strength until they were satisfied, often requiring people to stop what they were doing and go to the bathroom and pick or pull because until they did they would be unable to think of anything else. This thesis will work in conversation with anthropological and sociological studies on addiction, arguing that the BFRB body itself acts as a stimulus (Brodie & Redfield 2002, Ulrich 2015), highlighting the pleasure

associated with addiction (Bancroft 2009), and complicates the relationship between care and harm in BFRBs as well as other addictive behaviours like compulsive gambling (Schüll 2012).

The embodied urges of BFRBs are mentioned in much of the psychiatric literature, although fleetingly. Habit-reversal approaches to treatment focus on these urges as aspects of the body that can be overcome, describing the way that the mind can be altered, thus affecting the habitual movement of bodies. The idea that the brain is “plastic” and malleable is mentioned in positive terms, signifying the mind’s ability to change through training. Yet current BFRB literature rarely addresses the labour involved in this training, nor its effects on aspects of the self. As well as containing strong urges, another main reason that people find BFRBs difficult to overcome is due to the pleasure and satisfaction that they provide. Once again, these aspects of BFRBs are mentioned in most psychiatric accounts very briefly. This thesis will unpack these positive feelings, and consider what BFRBs *mean* to people. People described to me the ways that hair pulling and skin picking became part of the self over time. People said that BFRB were “part of me”, and that losing these behaviours would be like “cutting off my arm”. The fear and anxiety of changing behaviours is connected to a sense of self that is overlooked in current psychiatric discussions of treatment, and is one way that anthropological insights on the body can benefit BFRB research. Chapter One will describe this in more detail when considering changing temporalities and the life course, and shows how the BFRB body creates complex understandings of the self which can hinder recovery and which unsettles the desirability of recovery.

Hair has always been a particular interest to anthropologists, as Jacobs-Huey says, “hair appeals to anthropologists as a highly symbolic part of the body that offers insights into individual and social culture...[and] also provides individuals with a means of representing themselves and negotiating their place in the world” (2006: 4). Studies on hair have shown its unique diversity across the globe (Synnott 1987). Scholars have recognised that hair is an anomaly, being both public and private, simultaneously both

part of the body and disconnected from it (Hershman 1974, Tarlo 2016) echoing structuralist notions of the body (Douglas 1970, Kristeva 1982). Hair is personal and has been described as “an extension of ones person” (Chevannes 1995:112). Hair can therefore help us to understand notions of personhood and identity by looking at the way people care for it, cut or style it, cover it, or remove it. Hair is also social, highlighting the relationship between individuals and society (Frazer 1935), acting as a visual representation of mourning the dead, with the ability to communicate between people and across worlds (Leach 1958), as a religious symbol (Obeyesekere 1984), and as a sign of madness if not properly maintained (Tarlo 2016: 146). Hair has also been shown to highlight “opposites” particularly in terms of gendered divides (Synnott 1987). By observing hair practices, we can better understand social relations between different members of society as well as rites of passage (Hershman 1974). Clearly, hair is also highly political, and can act as a way of expressing resistance to social norms. Particular examples of this include the celebration of African heritage through the afro, Jamaican dreadlocks (Banks 2000, Chevannes 1995), and the feminist movement’s backlash against female hair norms (Herzig 2015, Lowe 2016).

Alongside anthropology’s fascination with hair, our undeniable colonial past reminds us of how closely implicated anthropologists have been in the racial classification of people (Rooks 1996). Hair texture is undoubtedly a marker of racial classification, reflected in cultural beauty norms still today (Banks 2000). Discrimination on the basis of hair can be seen through history (Caldwell 1991) and has been called into question very recently with new policies being introduced in New York City banning workplace discrimination of certain hairstyles (Blunt 2019). In Chapter Three I explore some of the ways that racial stereotypes were revealed to me in my fieldsites, both through the hyper-visibility of “white female beauty” in hair salons, and also through assumptions about Black women’s resilience to suffering in relation to hair loss. I argue that this rhetoric reinforces the stigma of Black hair and places higher value on white women’s beauty.

The most common forms of BFRB are hair pulling, skin picking and nail biting. Notably, all of these parts of the body grow, shed and reproduce, and as such often described as bodily waste products. They are also highly gendered, and the target of beauty campaigns frequently aimed at women, like those I saw displayed in the London underground during fieldwork (Figure 1).



*Figure 1: Advertisement for Perfectil*

Hair is one of the most valuable symbols of female beauty, with long hair considered a symbol of both femininity and social status for women throughout Western history (Synnott 2002). Yet, conclusions about hair in relation to gender are often made in opposition, as though men and women always experience hair practices differently (Synnott 1987). Those who have drawn attention to female hair loss have documented the severe shame and stigma felt by women experiencing alopecia (Williamson et al. 2001) and hair loss due to chemotherapy (Hansen 2007). Men's experiences of hair loss are less present. Tarlo's (2016) account on hair loss brings together the experiences of women and men to show that shame is present across genders. This shame is reflected in the demand for hair products and the unstoppable growth of the hair industry. She says, "The gap between the length of time taken to grow hair and the rapidity with which extension and wigs are consumed creates a permanent sense of tension in the market" (2016: 50). In Chapter Three, I offer some lived experiences from women who depend of these hair extensions in order to feel "normal" in



everyday life and critically discuss the absence of men in the advertising of these cosmetic treatments.

On hair removal, Herzig (2015) has compiled a detailed history of hair removal in relation to American cosmetic practices highlighting the ways that hair can act as a mode of agency and control. This work, like Tarlo's (2016), highlights the great value given to hair as a commodity. But the commoditisation of hair is not without racial and gendered stereotypes, and Tarlo claims that there are parallels between the racial classifications of hair during the colonial period to today's ethnic labelling of human hair extensions (2016: 167). The global hair industry demonstrates the demand for hair care products for different people, and Tarlo is told by her informants at a Mississippi hair trade show that Black college students are more likely to enter the hair care industry than whites because they are "hungrier" for hair (Tarlo 2016: 137). Tarlo discovers that this hunger for hair is tied to its transformative abilities. But these transformations do not come without effort, and while hair is a commodity it is also an investment. As Tarlo is told, "it's like a house. If you invest money in a house you better look after it! It has to be maintained" (2016: 140). This maintenance for Black women in particular requires "large investments of time, money and discomfort" (2016: 142). In Chapter Three I will show how the dependency on cosmetic hair treatments for trichotillomania involves both empowerment and risk, heightened by people's choices to share their stories with the press in exchange for discounts on their hair investments.

In comparison to the vast anthropological literature on hair, studies on skin are almost non-existent, except obviously in the context of skin colour and race. Dermatologists like Jowett & Ryan (1985) have explored the impact of skin conditions on everyday life, though skin picking is not discussed. Some authors have complained that skin disorders have received recognition for their "psycho-social" effects but hair disorders have not (Williamson et al. 2001). Although literature on hair is plentiful, stories of hair disorders and hair loss are still missing from anthropological accounts, with Tarlo

(2016) and Hansen (2007) perhaps the only anthropologists to offer perspectives on the lived experiences of hair loss. Cultural accounts on hair pulling have focused on the spiritual aspects of the practice in rituals. There is evidence that early Greeks tore out hair from their head and lay upon corpses of friends or relatives (Corson 1965), and examples of the Jain community in India who regularly pluck out all the hair from their scalp as a rite of passage that signifies detachment from pain (Issac et al. 2018). Hair pulling has also been used historically in art to depict frustration and madness (Gilman 1996). My thesis helps to fill this much-needed gap, presenting the first anthropological account of pathological hair pulling and offering a new perspective to anthropological work on hair.

The theme of visibility is central to notions of the body, and much can be said about the ways bodies are decorated, modified and presented (McDonald 2018). Turner's ([1980] 2012) anthropological account of the Amazonian tribe, Kayapo, describes the way bodies are decorated and highlights the relationship between skin and hair. He notes that illness is conceived of "the encroachment of natural, and particularly animal, forces upon the domain of social relations" which are polluted by way of the human body. Cleanliness thus requires a removal of "natural" hair from the surface of the body and transforms the skin from "natural" to a "social" (2012: 488). But hair is also important symbol that connects the self to the social world, signifying differences between tribal communities, and connecting parents and children well beyond social or emotional ties (2012: 488-489). Turner's work speaks to later kinship theories on mutuality of being (Sahlins 2011, Stasch 2009), which I will develop in Chapter Two when I describe the shared suffering connected to hair loss for parents and children.

People with BFRBs manage their bodies in particular ways, and in Chapter One I describe the way BFRB bodies are both revealed and concealed and the "techniques of concealment" that people use in order to hide hair loss and scars. These techniques themselves reveal perceptions of the self that tie in with scholarly work on stigma. Goffman's (1968) classic work on stigma and the management of spoiled identity

continues to be relevant here and will be utilised and built on in my thesis. In particular Goffman's attention to the visibility of stigma and the efforts that people go to in order to hide stigmatising attributes. More recently, Green (2009) has argued that the introduction of different technologies has allowed people to conceal illness more effectively, such as the use of anti-retroviral therapies for the treatment of HIV/AIDS. She argues that these kinds of advances lead us towards the "end of stigma". However, stigma is not just focused on the physical body, it is also internalised through experiences of shame. Goffman fails to address shame fully in his text, and is instead preoccupied with stigma from others, "normals" as he refers to them (1968: 15). These normal others are assumed to be strangers, members of the public, but does not include family members or health professionals. I complicate this idea of stigma in Chapter Two (family) and Chapter Four (medical professionals). In this thesis, much of the stigma associated with BFRBs comes from an internalised shame, and the fear of judgement from others. As I will show in Chapter One, shame comes from a lack of understanding and control of the embodied urges that hair pulling and skin picking involve. Feelings of shame are caused by the embarrassment of what the physical body looks like in the form of hair loss and scars. But people were also deeply ashamed of how this bodily damage was created, and the unusual rituals and sensory rewards that often accompanied repetitive behaviours - examining the hairs after pulling as well as feelings of pleasure or satisfaction. Techniques of concealment are used to avoid revealing the BFRB body but also to prevent explanations of how the BFRB body came to look the way it does. In my description of techniques of concealment in Chapter One, I will build on the work of Warin (2010) who examines the role of secrecy for people living with anorexia as well as the relatedness that secrecy can bring.

Goffman's exploration of stigma acknowledges that beyond the physical body, one's "known-about-ness" can increase the likelihood of stigma. Known-about-ness is the extent to which other people are aware that the person is ill, but it does not include the aspect of public awareness or known-about-ness of the illness itself. This thesis demonstrates that the level to which an illness is known-about can directly impact

those who suffer from it; measured in terms of visibility and recognition. As I will show in Chapter One, the lack of public knowledge on BFRBs influences people's experiences of feeling like "a freak"; similarly, in Chapter Two we will see how stigma from parents is also linked to lack of public awareness. Chapter Four will examine the process through which people come to learn about their condition as well as coming to know others who share their experience. We will also see how people in the community attempt to raise public awareness of these conditions through acts of biosolidarity. These aspects of my research show how experiences of stigma are experienced collectively and through a solidarity with one another, a group can attempt to combat future stigma and improve the known-about-ness of the community.

Important connections have been made by other scholars between stigma and the body, with Hardon & Posel (2012) showing the links between social understandings of shame and embodiment theory. This work speaks to the experiences of BFRBs as it shows how secrecy can be both a social and an embodied experience. In Chapter One I will show the ways that secrecy influences the way that people conceal the effects of their BFRBs, and how these techniques of concealment connect to embodied shame, and conflicting notions of the self. The stigmatisation of BFRBs has not been directly addressed in the current literature. This thesis unpacks stigma in depth, describing the ways that shame affects the perception of self (Chapter One) and in relation to family life (Chapter Two), showing that stigma is present in domestic as well as public spheres, but also how these spaces affect and shape each other. In my discussion on the ways BFRBs are made visible through the media, Chapter Three argues that the shame associated with hair pulling is reinforced by the way trichotillomania is represented in the press, and reveals the power dynamics that reinforce the idea that hair loss is shameful and ought to be concealed. Overall this work contributes to the growing literature on stigma in relation to health and illness, in particular the way that marked bodies are perceived by selves and others (Chandler 2016, Clare 2001, Lavis 2015, Warin 2010).

The lack of focus on hair and skin disorders in literature mirrors the poor visibility of BFRBs more generally due to their limited awareness. This thesis describes the different factors that contribute to this rising recognition, by unpacking the influence of the media (Chapter Three), the DSM (Chapter Four) alongside BFRB advocacy (Chapter Four). While this thesis describes the visibility of BFRBs in terms of public recognition, the profile of skin picking is important in this goal. In particular, medical anthropologists have rarely paid attention to skin disorders and the links between anthropology and dermatology have yet to be made.

### **Diagnosis and Medicalisation**

Within the social sciences, this thesis contributes to interesting discussions on the role of diagnosis to illness experience. BFRBs are not easily classified; they are to some extent “normal” grooming behaviours, that have become out of control. They are mental disorders, with a physical effect on the body. They are visible in many ways, and invisible in others. People living with BFRBs have similar contradictions and complexities in their experiences of them. As such, psychiatric diagnostic classifications have struggled to represent these behaviours through labelling, and many people in the community had frustrations with the descriptions and labels provided. However, these labels were considered deeply meaningful to my interlocutors and allowed them to attribute a name to their behaviour, which often shaped identity and led to intimate biosocial connections. This thesis aims to unpack the relationship between diagnosis and biosociality and show how labels and people with labels shape and emerge together.

Diagnosis has become a major focus of theories of medicalisation and biopolitics within the sociology and anthropology of health and illness (Blaxter 1978, Good & Good 1986, Brown 1995, Jutel & Nettleton 2011). There have been many critiques of medical and psychological expertise, stressing that the act of classifying illness expresses a hegemonic biopower (Foucault 1973, Illich 1976). My interlocutors felt

reassured by having a medical label, arguing that they felt more “normal” than they did before as they finally had legitimacy for their “unusual” behaviour. This idea speaks to other work on mental illness classifications. In the example of bipolar disorder, Emily Martin (2009) has argued that diagnosis moves people from “rational” to “irrational”, summarising that medical labels can have negative connotations. For BFRBs, it was the contrary, with people moving from abnormal to *normal* after finding out the name. Pathological labels are therefore viewed in a positive sense, leading to a reclaiming of diagnostic labels in terms of identity formation.

Concepts like “biographical disruption” (Bury 1982) have become popular ways of making sense of the ways identities can be altered through experiences of chronic illness, although rarely accounts for the positive aspects of diagnosis. Others have since suggested the term “biographical reconstruction” to combat this overly negative outlook. In the case of fibromyalgia, Homma et al. (2016) have shown how biographical disruption can lead to biographical reconstruction in self-help groups, showing the benefits of connecting with a biosocial group. This is important in the context of BFRBs, and in Chapter Four I will describe the way that people with BFRBs often experience both biographical disruption following diagnosis, though usually as a positive experience. Hacking (1995, 1998, 2007) has been instrumental in recognising the ways in which diagnosis and patient identities emerge “hand in hand” through looping effects. However, largely missing from Hacking’s theory, is the temporalities involved in looping effects. Hoover’s (2010) study on obesity and diabetes has highlighted a multi-temporality that exists in their diagnoses, where people are not just concerned with the symptoms they experience in the present, but are continually conversing about the past, and hoping for the future. In Chapter One, I will address the way temporality is described in terms of BFRBs, and Chapter Four will build further on the topic of changing labels and identities, highlighting the tensions that surround the changing labels of BFRBs. In line with ongoing debates on the DSM, I contribute to the idea that labels are not static, unchanging entities nor are they separate from

social worlds. Medical labels are socially constructed over time; and they are vulnerable to change.

Having already mentioned the importance of finding out the “name”, it is important to consider what happens when names change. In the case of trichotillomania, there has been much debate on this issue, both on the controversy of the name (due to the inclusion of “mania” as further stigmatising), but also ongoing discussions on which body of disorders they belong to. Suggestions made by TLC’s Scientific Advisory Board seemed to influence the change in classification that happened in the most recent 2013 DSM (Stein et al. 2010), moving trichotillomania from “impulse-control disorder not elsewhere classified” into the group of “obsessive-compulsive and related disorders”. While the ideal scenario would have been recognition of the term BFRB as a new diagnostic group, it was seen as a step in the right direction. In an ongoing effort to reshape the clinical diagnostic categories, TLC now insist on the term body-focused repetitive behaviour, in the hope that it will eventually gain DSM recognition. Perhaps unsurprisingly, the new BFRB label was not welcomed by everyone, and I observed much discussion on the new label throughout my fieldwork. Beckie0, the popular “trichster”<sup>4</sup> on YouTube spoke openly about this on her video blog channel where she rejected it emphatically. In this video, entitled “Trich Awareness Week / BFRB Rant” (TrichJournal, YouTube, 2014) she complains about trichotillomania being “lumped” together with other disorders, and how this will confuse the public and make individual experiences harder to communicate. She was concerned about “her disorder” getting lost within the BFRB category, especially in the context of BFRB awareness week which was previously an awareness week only for trich. The comments in response to Beckie0’s video, showed reactions from people with skin picking, who reminded her that they have been underrepresented until recently, and so they welcomed the inclusion of such a term. Beckie0’s “rant” is an example of the meaning attributed to psychiatric labels, and how they shape people’s identities in important ways.

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<sup>4</sup> “Trichster” is an affectionate name used in the community to refer to someone who suffers from trichotillomania.

The introduction of BFRB as a new label confirms the importance of labelling, and the ways that psychiatric labels can influence people's sense of self. But it also highlights the tensions between people living with different labels under the same umbrella, in this case the potential differences between people living with trichotillomania and dermatillomania. This was sometimes brought to my attention in support group settings, when a few people questioned the inclusion of skin picking attendees. However, this issue is more complex, as for many people, BFRBs are in a sense comorbid, and many people struggle with a variety of them at the same time (nail biting is common among most, for example). As I have mentioned, there is also a great deal of variety in peoples' experiences with BFRBs, and that the rituals involved mean that there is really no such thing as "classic" trichotillomania or dermatillomania, as all experiences are heterogeneous to some degree and thus the existence of specific diagnostic criteria is questionable in itself. Importantly for people with BFRBs, is the way diagnosis comes about, as this is rarely through interactions with doctors. Most of my interlocutors diagnosed themselves, finding out the name online or in the press and magazines. Interactions with doctors and professionals that followed diagnosis were often negative and disappointing, due to the lack of information and awareness that doctors currently have on BFRBs, especially in the UK. Therefore, this thesis expands our understanding of doctor-patient relationships, and support the argument that stigma from health professionals can lead to help-seeking avoidance (Chandler 2016).

In terms of patient advocacy, a growing number of scholars have recognised the power-shift between professionals and patients. In particular, this can circulate around resistance to psychiatric classifications. Brown et al. (2011) have highlighted the ways in which diagnosis can also lead to social movements, where people contest the labels given and actively campaigning against the "dominant epidemiological paradigm" that lies behind disease (2011: 940). This point emphasises that diagnosis is relational and can be changed or influenced through social movements. We can also see attempts to influence medical power through the notion of the "expert patient"



which is popular within medical sociology, and understands expertise as both lay and professional. When thinking about resistance to “experts”, Borkman (1976) describes this as “experiential knowledge”. In her social study of a selection of self-help groups, she observes that when patients are not given the deference they expect, higher priority is given to experiential knowledge in the form of self-help groups (Borkman 1976: 448). Similar concepts like “working knowledge” have been suggested by Lindee (2008) and Rapp (2003), and “authoritative knowledge” (Jordan 1977), all of which highlight the increasing value that is being given to lay expertise in experiences of health and illness. This thesis contributes to these notions of expertise; with my preference for the term “embodied knowledge” (Okely 1992).

Frequently missing from the current studies on BFRBs is the acknowledgement of treatment in broad terms. Interventions and treatment models are presented in line with medical models that usually involve therapeutic care between “professionals” and “patients”. The main aim of this thesis is to show the value that people place on community-led support networks. In Chapter Five I argue that biosocial connections can contribute towards recovery through collective self-care practices. These self-care practices were often based on the idea of accepting BFRBs rather than trying to overcome them. With the focus on acceptance as a form of recovery, I do not wish to undermine therapeutic or cosmetic treatments, but instead to present a multi-dimensional approach to “care” in which people shape their own recovery journey that often contradicts biomedical models of treatment. This thesis therefore reveals an irony to medicalisation, and shows that there can be a value in medical labels even when they do not lead to medical treatments.

### **From Biosociality to Biosolidarity**

Biosociality is incredibly important for people living with BFRBs, due to the isolation that many feel before discovering they “are not alone”. In this thesis, I unpack the concept of biosociality, demonstrating the way that biosocial groups are formed.

Often missing from discussions on biosociality is the process of finding and making a community. The term was first used by Rabinow (1996) to describe the social relations that are formed through the shared experience of a biological condition. Marsland (2012) has acknowledged the focus on the “social” over the “biological” in the context of HIV/AIDS in Tanzania, where the formations of biosocial connections are not dependent on disclosing illness diagnoses. As such, she suggests the term (bio)sociality. The question of what the “bio” means in biosociality is important, and is one of the reasons I welcome the use of the term, as BFRB experiences are centred around the body in ways that make social connections increasingly meaningful. In Chapter One I will describe the way that the BFRB body is felt, and the complex mixture of sensory rewards and shame that come with experiences of hair pulling and skin picking. This confusion has caused people to feel “out of control” in their bodies, and “like a freak”. As I will show, the moment of diagnosis allows people to connect with other people “just like them” and brings a sense of normalcy to their embodied experiences. Biosociality is important then because it allows people to communicate the way they feel about their to people who “understand”, without fear of judgement.

Despite the usefulness of the term, biosociality has also been critiqued, and Bridges (2011) has acknowledged that membership to biosocial groups is not without risks. Her ethnography on Black women’s reproductive health in New York City shows how biosociality can lead to further stigma and marginalisation as it reproduces racist discourses on health among “high risk” groups. My thesis demonstrates that biosociality is not at all straightforward, and it can exclude people, which I describe in Chapter Three. Unlike other work, my thesis acknowledges that biosociality is a *process*, where communities do not simply exist but instead people come together in various ways that require work from a number of people. In Chapter Four I describe the journey towards building the BFRB community, and the challenges that accompanied my own pivotal role in the production process. Some scholars have highlighted these productive aspects of biosociality, like Friedner (2010) in the Deaf community, and Rose & Novas (2005) who have shown how the groups that form

around biological classifications have a history of medical activism. But while the productive and activist elements of biosociality have been explored, my observations within the BFRB community told me that biosociality is often an intimate experience, kept secret from many other people in their lives. For others, biosociality triggered a call for action, with people feeling the need to make themselves and others with BFRBs visible through awareness-raising campaigns. To account for the differences in these biosocial journeys, I have expanded biosociality and introduced the concept of *biosolidarity*. This new term seeks to acknowledge the way some people turned biosociality into a cause for activism, including myself. As we will see in Chapter Four, biosociality and biosolidarity work in circularity with one another, where the visibility of the BFRB community creates increasing opportunities for people living in isolation to become part of the biosocial group. This “circle of biosolidarity” shows the way biosociality reproduces, allowing a community to become visible and to grow over time. The term biosolidarity has not yet entered the vocabulary of anthropologists, although it has been mentioned fleetingly in a few medical papers, but without being fully defined (Burgio & Locatelli 2003, Gaughwin 1995). By way of introducing this term, I define biosolidarity as the process through which biosocial actors move towards acts of advocacy on behalf of their biosocial group.

The theme of visibility is entangled throughout this thesis, and each chapter speaks to the varying ways in which BFRB experiences are concealed and revealed. I will show how the social aspects of living with BFRBs are connected to visibility and how a community comes into view. The theme of visibility in the context of health is most relevant to my thesis when considering the way that certain groups of people become recognised. This is tied into Hacking’s (1995) idea of “looping effects”, where he suggests that the labels and the *labelled* emerge simultaneously. Although, Hacking gives little attention to the lived experiences of this process of labelling. In my use of biosociality, I show the direct links between diagnosis and sociality, and add new example to Hacking’s concept that uniquely describes the process of looping as it occurred during my fieldwork. I also show how the BFRB community is actively

involved in the process of creating new labels and new ways of being seen through acts of biosolidarity. Other anthropologists have shown similar ways of how patient empowerment can increase the visibility of certain groups. Most prominently in the LGBTQ community, where visibility has played an important role throughout history pertaining to people's rights and recognition as a minority group, as well as identity formation (D'Emilio 1983). More recently, Gray's (2009) work on young LGBTQ people living in rural United States, follows visibility among the connections that are formed online. Gray demonstrates the way that "new media" can offer empowerment to young people who negotiate their visibility online. In the context of health, this empowerment has been shown to also involve risks, as described by Hardon & Posel (2012) in their work on confessions of people living with HIV/AIDS. In Chapter Three I will describe similar experiences of "coming out" my analysis of the way people's stories are represented in the media and the power relations involved in this process. I argue that the ways in which BFRBs are made visible involves the negotiation of empowerment and risk, and highlights the different tensions that can arise within the "TLC family".

## **Kinship and Care**

This thesis concerns kinship in a number of ways. Firstly, it brings the family dynamics of BFRBs into view, as only a small number of studies have looked beyond the individual experience (Franklin et al. 2011, George, Herman & Ostrander 2006, Hibbs et al. 1991, Keuthen et al. 2013, Wood et al. 2003). In Chapter Two, I explore how families are affected by BFRBs, paying particular attention to parent-child relationships. Through these examples, I show how BFRB experiences can be understood in terms of mutuality of being (Sahlins 2011), and contribute to the notion of illness as an intersubjective experience. The study of emotions and affect has quickly become a topic that has interested scholars across the disciplines (Lutz & White 1986, Röttger-Rössler & Slaby 2018), although the anthropological focus on affect within families is somewhat limited. In Chapter Two I disentangle the role of emotions

within the family and show how feelings of loss, sadness and guilt are intersubjective. This chapter highlights the role of gendered emotions and experiences of intersubjectivity, showing the important differences in how mothers and fathers care for and relate to their BFRB children. This thesis offers new perspectives on the notion of intersubjectivity in kinship studies, demonstrating how the simultaneous intimacy and distance of parent and child emotions can produce forms of care that are both loving and harmful.

The negative aspects of families have been the focus of few, most notable is Geschiere (2003). He describes the “dark side of kinship”, his focus being the risks of witchcraft in families. The idea of *care* as harmful within families is lacking in the anthropological literature, although it is hinted to in the work of Stasch (2009) and Scheper-Hughes (1993) who both describe experiences of mothering that conflict the notion that care from parents is always “loving”. Reece (2015) has more explicitly addressed the dark side of care, specifically in the context of families, arguing that care almost always involves crisis and conflict in Botswana. In Chapter Two I will build on anthropological discussions on care, arguing that care from parents to children contains elements of harm due to the limits of their intersubjective experiences of suffering.

Care and kinship are often used synonymously. After years of being largely ignored from anthropological discussions (Borneman 1997), care has brought increasing amounts of anthropological attention, although the term itself remains “fuzzy” (Alber & Drotbohm 2015:1). Although my interlocutors rarely used the word “care” to describe their practices towards one another, they did use the term “self-care” in relation to the self. When describing the feelings towards the community, they often used the word “love”. I will unpack both self-care and love in Chapter Five. Much of the literature on care is focused on the overly positive aspects of care relations, which Kleinman (2012) in particular has been critiqued for. My ethnography expands our understanding of care with a particular emphasis on the way that care within families can be harmful. This relationship between care and harm is incredibly limited in

discussions of care, although and some have shown how self-care can involve elements of harm in experiences of compulsive gambling (Schüll 2006) and eating disorders (Lavis 2015). I expand on their work in Chapter One when I describe the ways that hair pulling and skin picking often make people feel “better” and “worse” at the same time.

This thesis expands philosophical understandings of caring for the self (Foucault 1973) to include experiences of harm. I also build on those who have shown that self-care can be seen as a form of resistance to professional forms of knowledge and treatment (Ecks 2004, Hopper 1981, Mol & Law 2004, Waldstein 2010). Mol’s (2008) work in many ways engages with these debates on care, arguing that patient ideas of care are often in opposition to that of professionals, and that “care” does not always equate to “cure”. By expanding of the notion of self-care as a resistance to medical expertise, I show the different ways that people conceptualise recovery. I argue that recovery is relational, and in particular that self-care is often dependent on the collective self-care of others. Relapses are common in BFRB experiences, and recovery is an ongoing process. The key to this process is continued support from the community. Support groups, conferences and online interactions with people who share the BFRB experience can become some of the most meaningful and successful factors in living well with a BFRB. However, notions of recovery are also debated in this community, and I will present the tensions that surround different views on acceptance versus stopping -considering what these conflicts mean for future care in BFRB community.

The relational aspects of care have often been framed in terms of reciprocity. Kleinman has described this exchange as uni-directional; between “care-giver” and “care-receiver” (2015: 23), but in Heinemann’s (2014) ethnography on organ transplants, she recognises care as multi-directional. This has been expanded by Lesschafft (2016) through her work on Candomblé healing in Brazil. She argues that self-care and caring for others are intimately tied in “circles of care”. For people living with BFRBs, caring for the self is deeply relational, and is often dependent on support

from others within the biosocial group. In Chapter Four I will describe this in terms of collective self-care, and in Chapter Five I argue that collective self-care through the BFRB community can change the way the self is viewed. In this chapter I argue that self-care is dependent on positive feelings towards the self, and this is one of the reasons that my interlocutors struggled to care for themselves. The relationship between self-esteem and self-care further emphasises the relational aspects of care, and contributes to the limited anthropological work on self-esteem (Edmonds 2010).

This thesis and its focus on biosociality shows the importance of relatedness in the BFRB community, and demonstrates how biosociality can become a form of kinship. I therefore combine ideas of kinship with shared illness experiences. Solomon (2012) has described this as “social kinship” in his account of people who discover others with similar illness experiences, although kinship is arguably nothing if it is not “social”. The relatedness found in biosociality could potentially be framed as “fictive kin” (Johnson 1999: 370), although this term is less popular with kinship theorists. Weston (1991) has rejected “fictive kin” and argues that it adds further stigmatisation to the families described as fictive, as it questions their authenticity. In this thesis I refrain from using the term “fictive kin” to describe the relatedness within the BFRB community, instead I describe it using their own metaphor of the TLC family. Weston further shows how social connections among gay and lesbian people in San Francisco in the 1980s come to be seen as kinship that extends beyond blood and marriage ties, challenging previous notions of American kinship (Schneider 1984). This thesis also speaks to discussions on family members who do not share bodily experiences with their children, complicating notions of relatedness within families (Rapp & Ginsberg 2001, Solomon 2012). In this thesis I show the tensions that arise between parents and children, as well as within the TLC family; giving further evidence towards the idea that families are complex networks that cannot be restricted simply to the biological bonds between people (Carsten 2000). I should mention, that the family metaphor was only used by those who had attended TLC conferences and formed relationships with TLC. Many of my interlocutors extended this beyond the context of TLC conferences, saying

instead the “BFRB family”, but from my observations it seemed that the intimacy of TLC conference was what emphasised relatedness for this community. To acknowledge that the relationships formed in UK support groups, for example, were not described in kinship terms - I use the term TLC family rather than BFRB family.

## ~ Methods ~

### Demographics of the BFRB Community

This thesis is based on the lives of a selection of incredibly varied people across a sizable geographic space. I include men and women between the ages of nine-years-old and seventy-years-old, from varying ethnic and socioeconomic backgrounds, living with hair pulling and or skin picking disorders, residing in either the United Kingdom or the United States. My ability to account for the differences present in these personal and social aspects is limited in this thesis, and would probably consume an entire thesis itself. I therefore mostly concern myself with the similarities within this wide sample, highlighting cross-cutting differences. Much could be said about the high number of middle-class, white women that largely made up my sample, which I briefly address in Chapter Three in relation to the image of the “white female TTM sufferer” in the media. However, I do not dwell on socio-economic status of my interlocutors despite acknowledging the inaccessibility of cosmetic treatments and TLC conferences.

I originally set out to study experiences of trichotillomania only, but the decision to include skin picking experiences was influenced by the push for more skin picking inclusion by TLC. Additionally, I realised early on that there is often a blurring of BFRB experiences, with many people experiencing both hair pulling and skin picking tendencies simultaneously. Admittedly, my interlocutors also described their struggles with a number of other BFRBs including nail biting, cheek biting, leg shaking and nose picking, but I chose to focus primarily on the BFRB that affected daily life the most.



However, due to the lower profile of skin picking, and my late decision to include skin picking experiences, there is not a balanced view of skin picking and hair pulling narratives in this thesis.

While this thesis does not attempt to account for the wide range of differences between the vast numbers of people that make up the international BFRB community, important differences will be highlighted in various chapters when discussing the way that this community is formed. In particular, Chapter Four will address the challenges of finding and becoming part of a biosocial group. Chapter Three will consider the different types of people who are often under-represented in this community, and will address visibility in relation to gender and race. Chapter Five will discuss notions of treatment and recovery which are of course context dependent and involve important differences within the British and American healthcare contexts.

My decision to include both American and British experiences in this thesis was down to a lack of perspectives in the UK context that I considered essential to this investigation, namely professional and parent experiences. There are, of course, important differences between these societies I have been unable to fully address in this thesis. Some of these differences, between American-ness and British-ness, came up in conversations, most notably among my British informants. These differences were often discussed as tensions, and concerns a general politics of representation that will be present throughout this thesis. The visibility of TLC as a leading organisation was frustrating for some British interlocutors due to its physical basis in the United States. People complained about not having something “here”, and that although TLC was a good resource, it felt too “far away”. In relation to the conferences, this was obviously true, and involved the high cost of travel in order to attend. But other differences such as language and character also came into this feeling of TLC as an organisation not being able to represent the British experience. American “confidence” was frequently mentioned, as an enviable trait in young people who

seemed comfortable to share their experiences on YouTube videos for example, which felt unachievable for British people who described themselves as shy and reserved. The BFRB community is clearly fragmented, diverse and divided by social and geographical differences. But the community is also deeply connected by the similarities between people, in spite of their differences. People with BFRBs came together through the shared embodied experience of that often cut through social differences like class, race or gender, but at the same time people felt excluded by these very same factors. At times, I do refer to “the community” as a whole, but I recognise that a community is not as a static entity to be taken as face value. Instead, I describe the community as a biosocial group that emerges through a social process, which is fragile and constantly changing.

### **Disentangling the Field**

My initial view into the trichotillomania community came in 2012, when I entered into the vast world of online support groups to conduct research for my master’s dissertation. For this short project, I decided that an online ethnography was best suited. The internet had already become an important tool for me in my preliminary search for research participants, and I had been relying on the only UK website for trichotillomania support to make contact with people living with the disorder (Trichotillomania Support UK). My research plea was posted on this website, and very quickly I had responses from several people, and soon my connections began to snowball. One of my early contacts was Jude at The University of Glasgow, who suggested I join a support group on Facebook. I was a little embarrassed that I hadn’t considered this as a space where people might gather, and was surprised to find numerous Facebook support groups for people with trichotillomania, containing thousands of sufferers worldwide. The master’s research showed me the importance of online spaces, but also highlighted some of the challenges of including the internet as an ethnographic field site which required further thought for my PhD fieldwork preparations.

Anthropological work on social media sites like Facebook, remain limited despite virtual ethnographies proving useful (Boellstorff 2008). One of the challenges of doing ethnographic work online is the ability to include participative as well as observational aspects. In the presence of the Facebook support group, as someone living with trichotillomania I was well-placed to become a participant observer, although often I felt more of an “observing participant” (Tedlock 1991). Within sociology, Baym (1995, 2000) has discussed her role as “participant observer”, having already been a member of her online community prior to her fieldwork. Høybye et al. (2005) describe conducting participant observation within an online forum for women with breast cancer, but do not mention in their paper whether their participation comes from personal experiences with the illness. This disclosure was important to me, and I made sure to share my personal story when joining any new groups, and informed everyone that I was conducting research. Since I do not consider myself to suffer from skin picking, I decided not to join any of the dermatillomania Facebook groups.

For my PhD research, I realised that online spaces cannot be viewed as independent social spheres, but rather I saw online communities as an extension of everyday life. I was aware that this social setting may involve identity shifts and aspects of performance for people, between online and offline. In order to account for differences between online and offline spaces, I chose to only engage in conversations on Facebook forums with people I was also meeting in person, and who I knew had fully consented to my research. Beyond this, I regularly observed the general discussions online to reconfirm that my observations in the community were representative of the types of topics that were arising on Facebook. Of particular use, was observing the sharing of news articles online, allowing me to analyse the visibility of these public representations of trichotillomania. I will discuss these articles in Chapter Three where I describe the presence of trichotillomania in the “public culture”, by which I mean: “all the products of what is commonly called the ‘media’” (Ortner 1998: 414), including newspaper articles, television and documentary films. My PhD fieldwork commenced in June of 2015, just a few days following my Board

Review, I caught the overnight bus from Edinburgh to London. In collaboration with Jennifer Raikes of TLC, Dhaya had organised the first ever UK workshop for BFRBs, to be held at Kings College London. That bus ride was the first of many journeys that I would take during my sixteen months of fieldwork, spanning much of the UK.

Early on in my plans, I had decided not to limit my field sites to any one location. My own knowledge of hair pulling informed me that secrecy and shame played an important role, and so it was important that I allowed people to participate wherever possible, as I wanted to give value to their willingness to take part. My call for participants was launched on the Trichotillomania Support UK website and from there I received around thirty replies. With the exception of a few people in Northern Ireland and Wales, I arranged to meet everyone in person for an initial interview. In just the first few months of my fieldwork I visited: London, Linlithgow, Arbroath, Dunfermline, Stirling, Manchester, Sheffield, Coventry, Havant, Glasgow, Hitchin, and Rugby. Fortunately, the pace began to slow by November as I was suffering from burn-out during my stops back in Edinburgh, where I also had a wide range of people who wanted to meet. I soon established rapport with key informants in London and Edinburgh, and began to divide my time between these two locations.

In addition to meeting with individuals, I contacted a professional salon that provided treatments for women with hair loss. Named after its owner, Beverley, the company has studios in all over the UK and US, including Edinburgh, London and Manchester. Beverley has been working as a hair stylist for over thirty years, specialising in treatments for women with hair loss. Her main product is a piece of pioneering cosmetic technology called the Intralace System which is woven into strands of existing hair through thin mesh, and sewn in to cover areas of baldness while looking and feeling like natural hair. She also offers a selection of hair extensions, wigs and sprays designed to cover baldness on various parts of the scalp. Her clients visit for a variety of hair loss reasons, including alopecia, chemotherapy and trichotillomania. At the same time as finding the websites for her salons, the search engine showed me

links to news articles about her services and a Channel 4 documentary called *Girls on the Pull* where she describes her treatments for compulsive hair pulling through the lives of four women. It was clear to me that I had found one of the few British experts in “TTM”, as she calls it. I met with Beverley in June, and in October she emailed all of her clients my research information. That same evening came a flurry of emails and phone calls from a further 30 or so women wanting to take part.

By the end of fieldwork, I had conducted interviews with a total of 30 women across the United Kingdom, and 5 men, as well as 4 of their partners. Around 10-15 of these people went on to become key informants. Our meetings took the form of informal interviews, and were often conducted in public spaces like cafés and restaurants. A few interviews were done in people’s homes, and after some time I was invited to stay with several key informants, making it possible to observe family and domestic life, interview some partners and meet their children. With the contacts I met through Beverley’s salon, I attended regular appointments at the Edinburgh salon with 3 women, and got to know the staff well during these visits.

Despite reaching out to mental health service providers, my interactions with professionals in the UK was limited to interviews with the salon staff and one hypnotherapist. Given my links with TLC, I decided to include the perspective of professionals by adding further American fieldsites. In 2016, while I was in the US for the TLC conference in Dallas, I travelled to Washington, DC to spend a week at the Behavior Therapy Center (BTC),<sup>5</sup> run by one of TLC’s leading members of the Scientific Advisory Board. During this time, I was able to interview therapists, as well as clients and a few of their parents.

As well as the limited number of UK professionals, I also struggled to meet with parents of people living with BFRBs in Britain. Therefore, my attendance at TLC conferences in 2015, 2016 and 2018 allowed me to conduct further interviews with parents. The TLC

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<sup>5</sup> A more detailed description of BTC will feature in Chapter Four.

conferences were essential to my understanding and shaping of the BFRB community as they were spaces where families and professionals interacted together. These conferences not only allowed me the chance to hear about research updates and meet families, but they also showed a very clear view into the effects of community support for BFRBs. In America, I interviewed a total of 9 people living with BFRBs, 7 practitioners (therapists and researchers) and 5 parents.

I had originally planned to include focus groups in my research methods. My initial participants had expressed a great interest in meeting other people and were keen to take part in a potential focus group. However, following my first few meetings with individuals, it was clear to me that my role in this research had changed. For many of my interlocutors, their first interview with me was their first time meeting anyone else with a BFRB. I was struck by how easily people opened up to me, sharing intimate stories about their lives on these primary interactions. Not only was there an apparent trust in me, I often felt an intimate bond with people, and an unexpected familiarity. This feeling was reciprocated by my interlocutors who said “it’s like we’ve known each other for years”. This connection between people with shared experiences of illness is evident in other contexts, and has been described as akin to meeting long lost friends or relatives (Solomon 2012), but has rarely been described in relation to the role of the ethnographer. Undoubtedly, this bond that I shared with people aided their trust in me and strengthened rapport between us in a short amount of time. It also affected the narratives that they shared with me, much of which they admitted had never been disclosed to anyone else in their lives before. This reminded me early on of the responsibility of my position, and the value in these experiences that people had so trustingly shared with me. But these moments also revealed to me the way that sharing intimate, secret stories with someone who “really understood”, brought a great sense of relief. I was further surprised by how often my interlocutors told me that they felt “better” after talking to me for the first time, like “a weight had been lifted”. As my research unfolded it was clear that the silence that surrounded many private aspects of living with a BFRB had put a heavy strain on relationships with family

members and loved ones, and that many people were looking for the opportunity to talk.

From these conversations it was also evident that BFRB support in the UK was non-existent, and most of my interlocutors had struggled to find a space where they felt comfortable to talk with professionals, or receive any medical care. I had a real sense that by putting myself “out there” as a person who wanted to listen to BFRB stories, I was now one of the few people who could do something for this community. This feeling of duty was strong early on, but was also mixed with the burden of responsibility. I realised that I was neither professionally trained nor personally able to take on the role of a therapist to each individual that I was meeting, as I felt myself worrying for many of these men and women after hearing the struggles they encountered in their lives. It was then that I considered one way to share the responsibility would be to set up a group where the different people I was meeting could meet one another, and form bonds that went beyond just me. So, in October 2015 I decided to start a support group in Edinburgh. Following this, Dhaya and I set up another group in London in January 2016. Both groups have continued to run over the years with numbers increasing each month. These support groups were the first ever in the UK for BFRBs, and have also inspired others to start their own groups in other parts of the country. Importantly, my decision to start these support groups was instead of a research focus group, but they were not intended to be spaces for me to record people’s experiences. Since not everyone in these groups was participating in my research, I did not record any conversations or take notes during any meetings, and I always disclosed to new members that I was conducting research outwith these spaces. However, many of my research participants did attend the support groups, and so I was able to observe their journeys alongside this new support network, and group meetings often triggered deeper conversations with my informants outside of these spaces. Ultimately, my ongoing participation in these support groups has strengthened my role in this community and informed my understanding of the way support groups can influence recovery for BFRBs.

Opportunities to conduct participant observation in my fieldwork were limited. Facebook support groups were one of the few spaces where observation was possible, but this often felt covert and dishonest. In other fieldsites, I made a few attempts to “blend into the background” which often made my interlocutors uncomfortable. For example, one time I accompanied Olly to work at The University of Stirling where we sat in his office awkwardly for a few hours and he struggled to explain to his colleagues who I was and what I was doing. Participant observation came more easily as I was welcomed into people’s homes, invited to the salons, visited BTC, and attended TLC conferences. But ultimately the focus on interviews is reflected in this thesis due to the importance of talking for my interlocutors, and thus the importance of narrative.

### **“Science and Storytelling”: The Anthropological Method**

The absence of BFRB voices in current research frustrated me as an anthropologist but also as someone living with trichotillomania. My interlocutors did not seem overly bothered by the absence of narrative in the BFRB studies, and arguably there were enough autobiographical accounts to fill this gap for lay people. And yet, when I returned to the TLC conference in 2018 to present my findings to the community, I received an overwhelming positive response to my research poster which contained detailed quotes from my interlocutors. People seemed pleasantly surprised that research could be presented in this way, and a student researcher commented: “I just think [ethnography] is the perfect method for this community because it’s science but it’s also storytelling”. This message epitomises one of the goals that this thesis set out to achieve: to bridge the gap between quantitative psy-research and the voices of the BFRB community.

The benefits of narrative are well-documented in medical anthropology and social sciences of health (Good 1992, Kleinman 1988, Nettleton 2006), but there are obvious limits to narrative in anthropological representations, particularly when dealing with complex embodied experiences. Ethnographers have used their own bodies to



enhance narratives in ways that attempt to represent those they work with. In Wacquant's (1995) ethnography on boxing, one of his interlocutors quite adamantly says: "There's no explanation for the feeling you got when there's, y'know, two thousand people screamin' your name... Right then it's just a feeling that, you just can't even explain, I mean I get the goosebumps just thinkin' about it! You - you can't explain it" (Wacquant 1995: 512). The challenge for the ethnographer then is to find ways to capture these inexplicable embodied feelings that cannot easily be put into words. While Wacqaunt attempts to become a boxing body, my own BFRB body allowed me to some extent to better understand the narratives presented to me. However, as BFRB experiences are deeply heterogeneous, personal to each individual in complex ways - my own experience will never be the same as someone else's and this is why narrative becomes crucial. So while I acknowledge that my embodied experience brought insight to my methods, and my ability to elicit narratives, I follow Chandler in her description of being a researcher faced with the "insider" status, "I am clear that my experiences inevitably shape how I analyse and interpret the practice of self-injury, and this includes the importance of my embodied experiences of self-injury and living with a self-injured body" (Chandler 2016: 16). The role of my own body was a key aspect to my methodology and I knew I would be conducting "embodied fieldwork" (Okely 2007), whether I wanted to or not. Not only did my BFRB body aid access into this community, it shaped my research questions and analysis in important ways. My own experiences of shame and stigma having lived a life with trichotillomania gave me insight and sensitivity, informing the themes that are the focus of this thesis. This autoethnographic approach to research worked for me both as a practical method, aiding and shaping my relationships with people in ways that would have otherwise been challenging. However, I would argue that the subjectivity and self-reflection that was necessary in this project, is equally important to any type of research conducted *by* people, *with* people - especially when that research involves asking about lived experience of illness. Therefore, in this thesis I place great value on the narratives of my interlocutors, while at the same time acknowledging that individual narratives are shaped by their social context and as I will show, are influenced strongly by

biomedicine (Chapter Four) and the media (Chapter Three). Recognising the limits to narrative, I attempt to bring multi-sensory elements to peoples experiences of BFRB, by using descriptions and images of art work by one of my key informants, Liz.

This project involved great methodological diversity that I consider to be well-suited to the context of BFRBs. The ethnographic approach importantly includes the social aspects of BFRBs often missing from other methodological models in the psychiatric literature. In my research I have included a wide selection of people and spaces in its sample and field sites. While I am well aware of the reasons behind scientific and quantitative approaches to sample selection for the purposes of analysis and measurement, I seek to show how an ethnographic methodology allows a wider view of this community to become visible. My variety of fieldsites, mixed methods and wide sample offers a more accurate representation of what the BFRB community “looks like”, with all of the complexities that are involved in this diverse, global community.

### **Ethical Considerations**

Due to the secrecy and shame associated with living with BFRBs, ethical considerations were at the forefront of my mind throughout this research. Every effort was taken to ensure the confidentiality of those I met, from asking each person to choose a comfortable meeting place and assisting them in creative cover-ups when colleagues, friends or strangers asked, “How do you know each other?” I have attempted to protect the personal identities of those who feature in this thesis through the use of pseudonyms, with the exception of a few who were happy to be named.

This project raised several ethical dilemmas that I have tried to overcome throughout the process. Firstly, I often questioned my ability to care for the emotional needs of those who participated in this research. More than I had anticipated, I was faced with worry and concern for people I met after they shared with me their struggles with BFRBs, combined with feelings of self-disgust and depression. Many of my

interlocutors were battling negative emotions as a result of their BFRB, and most of them had little or no support to manage these issues. I found myself wanting to regularly check-in with some people in particular, as I worried about their mental health in times when I wasn't able to visit. I was also keenly aware of the potential of my research to enhance negative feelings and unsettling memories. This was particularly the case for Shirley, who stopped contacting me after our first interview. After several attempts to get in contact with her failed, I continued to reach out despite my worry of being a nuisance. Fortunately, after some time she responded, and we went on to form a good relationship, although she admitted she found our first meeting difficult and that it actually made her pull her hair more in the following weeks.

My relationship with Shirley highlighted another ethical concern that I tried to manage with a variety of people, and this was my willingness to share treatment advice. Bearing in mind that BFRBs have very limited treatment options, with therapies and medications unlikely to have long-term effects, many of my interlocutors were keen to hear my opinion on what they could do to help themselves. People considered me to be in a position of expert knowledge and therefore presented me with their questions to be answered. To this, I chose to be honest, and given that that much of my knowledge on BFRBs was based on research that was accessible online to most, I willingly gave information about a variety of treatment approaches to my interlocutors as they requested. I was well aware of the problems that might ensue had I condoned certain medications or encouraged people to take certain methods, but I did not do so. With Shirley, our conversation had led to treatment options, and I eventually told her about the recent research done by TLC on the efficacy of n-acetylcysteine (N-ac) for hair pulling.

Once she had contacted me again, she asked me to forward her the report, which I did. Shirley then went on to order N-ac and begin the course as recommended by TLC's clinicians, and saw almost immediate results. In the days that followed, I received a

burst of emails from her updating me on her progress: “I only picked the N-ac on Friday, but... I really feel a BIG difference and it’s only Saturday!!!! Amazing. Will keep in touch”. On Monday she wrote: “It is incredible, still working so well, occasionally I’ll raise my arm and start twiddling BUT what I can do is stop it now”. On Tuesday she said: “Hi BB, I am so pleased with the N-ac, although I probably didn’t admit it even too myself I would normally wake up in the middle of the night twiddling, to the point I couldn’t get back to sleep, but I realised last night I haven’t done this since the N-ac, my hair is also feeling different, possibly that I can feel so much of the regrowth...”. About a year after finishing fieldwork, Shirley emailed me to ask about the birth of my son. In it she wrote: “from my perspective YOU helped me understand what I had to deal with, which I didn’t know before I met you, so as far as I’m concerned your work has (just about) cured me and I thank you very much, love Shirley”.

I share this story, not to claim that I was able to “cure” Shirley, but to combat some of the concerns in social research about the role of the researcher. In my opinion, withholding information from Shirley and others about potential treatments and therapies for BFRBs would have been an unethical course of action, and would likely have affected my ability to form trusting and meaningful relationships. These decisions were not taken lightly, and certainly increased my worries about people knowing that they were likely to trial new remedies based on my counsel, but through directing people to TLC and by setting up support groups, I was able to share the responsibility with others who had a range of expertise beyond my own.

Another important ethical consideration was my own mental health throughout this process, which I made attempts to protect before entering the field through several therapy sessions. Despite this being useful a useful method of preparation, the experience of “seeing myself” in the younger faces at the TLC conference, caused me to reflect on my childhood when my hair pulling was at its worst. Even now these are aspects that I will likely spend a long time processing. My fieldwork was particularly intense due to the multi-sited nature which did little to ease my existing anxiety. Not

only the regular travelling, but the added online space meant that I was always observing and collecting data, between field sites or while looking at Facebook on my phone. The process of doing “embodied fieldwork” also meant that I rarely felt able to “switch off”, and even when I was not with my interlocutors, I was even more aware of my own BFRB body, from which I was unable to escape. In many ways, the anthropological methods I used during fieldwork worked as my own tools of self-care; the ongoing process of reflection allowed my thoughts to come together in ways that helped me to keep a track of how I was feeling. My fieldnotes also acted as both a personal diary and a reminder of how busy my travel plans were getting and helped me to acknowledge and foresee when things should slow down. Luckily I was also able to stay with family and friends during my time in the various sites and cities, which gave me much-needed solace and the opportunity to offload during my fieldwork. The support groups also helped in this respect, and although they were sometimes stressful to facilitate, they often became a safe space where I could express my feelings. After fieldwork, I found my ongoing immersion in the community a continued struggle, and somewhat hastily, I made the decision to delete my Facebook account soon after I had completed fieldwork. My departure did little to ease anxieties, and instead made me feel as though I had abandoned my community, a guilt that many anthropologists likely feel when we leave our field behind. This decision was also influenced by colleagues who recommended “distancing” myself from fieldwork in order to fully embrace the process of writing up. On reflection, even without Facebook, I would never have been able to create this distance, and instead the closeness and continued contact with my interlocutors has been a welcome support.

Ultimately, while this project was approved early on by the University of Edinburgh, the ethics review process still did not prepare me fully for the predicaments that arose in my fieldwork and after. I mention this not to claim that fieldwork is meant to be “easy” or “comfortable”, but because I think too often anthropologists are expected to deal with the emotional and physical challenges of fieldwork, unprepared for the risks before we embark and unsupported through the situations as they arise. I was

fortunate to receive the support and care from a number of staff and peers during my challenges, but even so I strongly believe that the prevention of risk that we take seriously of our communities, should extend to our own personal experiences. Admitting that fieldwork is hard in many ways should not be something we are ashamed to do.

### ~ Overview: Unravelling a Thesis ~

This thesis begins by laying out the individual, embodied experiences of living with BFRBs. Chapter One describes the ways in which people with these behaviours hide, using various techniques of concealment to cover hair loss and scars in order to keep their BFRB a secret. This process of hiding aspects of the self becomes arduous and difficult to maintain, often causing people to avoid social situations where they may be revealed. Here I will show how it is important for people to keep the visible effects of their BFRB hidden; and we will see that the visible effects are just one element of what it means to suffer from hair pulling and skin picking which involves complex embodiment. This chapter shows how revealing the BFRB body can be risky, and argues that techniques of concealment offer people a sense of normalcy throughout the life course.

Chapter Two show the importance of kinship in the thesis, and through examples from parents it becomes clear that parents and children share a mutuality of being with one another, with intersubjective experiences of different emotions. I expand on Sahlins' (2011) notion of kinship as mutuality of being by highlighting the way intersubjective emotions are gendered, and intersectional, paying important attention to the *limits* of this shared experience. I go on to show the difficulties that people face in communicating their BFRB experiences to loved ones and family members. In this chapter I explain the frequent frustration felt by people living with BFRBs at the lack of understanding coming from close kin, which often involved cruel remarks, physical punishment and embarrassing comments. These experiences, frequently occurring in childhood and adolescence, had a long-lasting effect on my interlocutors, and

reinforced the isolation, confusion and shame that came with living with a BFRB. Examining the limits of intersubjectivity in families, I argue that parents struggle with the realisation that, despite feeling the pain and sadness of their children - they are unable to control their child's behaviour. Within this struggle is where we observe care practices that are misinformed, and often harmful. The limits to intersubjectivity not only creates tensions among non hair pulling parents with their hair pulling children, but is reflected in the "embodied risks" of passing on BFRBs to another generation. In these intergenerational experiences we begin to see how self-care practices are shaped by the memories of care in the family, and subsequently the collective self-care that is sought out in the TLC family.

In Chapter Three, I follow the experiences of women who have revealed their BFRB to the press, and show how this visibility involves a negotiation of both empowerment and risk. Focusing in on the particular form that these representations take, I explore the way that trichotillomania is viewed in the public culture, and how current media coverage in the UK fuels many common misconceptions about hair pulling; who it affects and how it ought to be treated. I describe the power and influence over the media enjoyed by British salon owner, Beverley and I argue that the focus on cosmetic treatments for trichotillomania reinforces many of the gendered and racialised assumptions around the condition, promoting a hyper-visibility of the "white female sufferer". This chapter introduces some of the tensions within the BFRB community surrounding recovery, that are largely split between acceptance and cessation.

Chapter Four describes the relationship between diagnosis and biosociality, following the way a community is created and subsequently makes itself visible. I describe the moment of diagnosis or finding out "the name", when people often experienced a sense of self-transformation. I also show the limits to diagnosis and how the medical labels of "trichotillomania" or "dermatillomania" brought disappointment, as they rarely led to treatment options or professional care. Here it becomes clear how practices of self-care become a necessity for BFRBs, and self-care is aided by the

biosocial group. Contrasting the earlier chapters that focus on stigma, we see that experiences of stigma can be alleviated through connecting with other people who have BFRBs. However, biosociality is not always straightforward and by building on theories of biosociality and the looping effects of diagnosis, I show how the formation of a community involves hard work and regular challenges. Recognising the weaknesses of biosociality, in this chapter I present the notion of biosolidarity; demonstrating how people improve the visibility of BFRBs through productive acts of advocacy.

Chapter Five will build on the various elements of the thesis and show how biosocial networks have the potential to shape notions of recovery. I describe the intimate relationships formed at TLC conferences, and the way that this community is referred to as a family. This notion of family is based explicitly on care and love, and becomes meaningful for people who often felt that these aspects of compassion were lacking in their familial interactions earlier in life. The love that comes from the biosocial community, has a direct effect on the self and in this chapter I argue that love in the TLC family forms the basis of collective self-care, which makes individual self-care possible. I show how many people in the BFRB community use this self-compassion towards a form of acceptance as recovery, which is clearly seen at TLC conferences with people removing their wigs and techniques of concealment in the security of this space. Echoing anthropological work on kinship and care, I will show that the TLC family is in many ways based on idealised notions of kinship as loving and caring, but that tensions that are also present within this family; therefore, highlighting both “circles of care” (Lesshafft 2016) and “conflicts of care” (Reece 2015). This chapter connects with the main points of Chapter Two, arguing that the TLC family involves a mutuality of being that involves both connection and separation, intimacy and distance, love and conflict. Importantly, I follow the tensions within the TLC family surrounding future treatments, and the role of obligation in funding these treatments, that highlights TLC’s complex role as both a support network and a non-profit organisation.



I conclude my thesis by considering the future of the BFRB community in the context of new research surrounding precision medicine initiatives. Here I consider how the role of biosocial groups may change in the face of new ways of viewing and treating mental disorders like BFRBs.

### **Ethnography as Biosolidarity**

This thesis is, in itself, my act of biosolidarity. On the last evening of the TLC conference in April 2015, before returning to Edinburgh, I made the decision to “come out”. Despite many of my close friends and family knowing that I had struggled with compulsive hair pulling since childhood, it was something I had tried hard to conceal in my “professional” life since leaving high school. I was very much hiding a side of myself, feeling as though my hair pulling was a “weakness”, and that I had to wear a mask in order to keep it hidden and pretend that I was someone different. That evening I wrote the following post on Facebook:

This weekend I attended a conference in Washington DC. I went as a researcher aiming to learn more about a topic which has been both misunderstood and under-diagnosed. The focus of my entire PhD is Trichotillomania. It is a condition that causes people to pull out their own hair. I would like to personally stand up and honestly, confidently say that I have struggled with trichotillomania since the age of 9. This has driven me to research this condition with the hope of increasing awareness for fellow sufferers. This weekend I met those people in person. I made friends with people who have spent years struggling alone, feeling ashamed of the behaviour that they cannot control. I spoke to parents of children who suffer silently with this issue. I reached out a girl, aged 9, who, just a few days ago, couldn't look me in the eye due to the shame that she feels for this 'thing' that she does. Today we are more connected. Today we feel less alone. Today I have decided that I will not hide this side of myself anymore, or feel ashamed of who I am. I hope tomorrow will be a different place for all of us (April 12<sup>th</sup> 2015).

The purpose of my work stretches far beyond the limits of this thesis, but I hope to guide the reader through my journey, following the lives of my interlocutors, who helped me to simultaneously capture and create this community. The research I

present here is an important view into a biosocial group that is emerging with great potential and strength, bringing academic and public interest to the world of BFRBs. Through their lives I hope to improve our understanding of what it means to live with a chronic, confusing mental health disorder that has very physical, visible effects on the body. I hope to expand our knowledge of how families experience the effects of mental illness, and show the value in all the conflicting ways they attempt care for one another. This work will also broaden the scope of medical anthropology and the social sciences of health in relation to diagnosis, medicalisation and ideas about recovery. Through this thesis I have shared a personal journey with my interlocutors, and I am proud to present myself within this community and on the pages of this work alongside them.



## Chapter 1

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### “Disorders of Hiding”: Concealing the BFRB Body

Nicole’s first email to me arrived in August 2015. She wrote: “I have had TTM since the age of 15 / 16 (over 20 years ago) and have only just started reaching out for help and support with it very recently, as the shame of having this condition has prevented me acting sooner.” Following some emails back and forth, we agreed to meet for the first time in Edinburgh’s New Town, in a café I had suggested after she said she was comfortable meeting in a public place. It was a sunny Wednesday morning in October. As always in my emails I had given a brief description of myself to make it easier for us to recognise one another, to which Nicole had responded: “I have auburn hair and will be wearing a light grey fleece”. When we found each other in the café, she joked that it felt like a “blind date” and said “I almost wore a flower in my hair!” Nicole is tall, with straight, shiny red hair, her face lightly dotted with freckles. When we met for the first time, she was extremely smiley and inviting. In our first interview we talked excitedly for over two hours, laughing frequently. I came away from that meeting feeling as though we had formed a strong connection, and in the months that followed we met regularly and became good friends. During our first meeting, she gave me a detailed overview of her life with trichotillomania, while intermittently laughing at herself. She has a great sense of humour and commented: “I never thought I’d be able to laugh about this”. But in between the joking she reflected on the daily worries associated with keeping her trichotillomania hidden:

You’ve probably experienced this - you know if you have anxiety dreams where you lose your teeth? And the minute you wake up you’re like, ‘that was a classic anxiety dream’. It makes you realise how much your own perception of the face you present to other people is tied up in just your *dental wellbeing*... Hair is also *so huge* and for people that suffer from TTM – it’s just constant, because you can’t hide it - well I mean you *can* hide it, but it’s always on your mind about whether it’s concealed or not [Nicole’s emphasis].

She went on to tell me about the anxiety she felt trying to keep herself concealed, and how this prevented her from doing certain daily activities.

It's been such a long time [since] I've been underwater when I'm swimming... I wear [contact] lenses, so if I wear waterproof eye mascara it really makes my eyes hurt for some reason, so I don't tend to wear it, but it does mean that if I go swimming, or, because I'm out in the hills an awful lot, and if the weather is atrocious I have to be very careful about covering it, and it's *those little things*, that if you don't suffer from it, you don't even think about it, but when you do, it's just a *constant* reminder of what you have [Nicole's emphasis].

On first impressions, it would be very difficult to know that Nicole had chronic hair pulling. She had recently chosen to have her eyebrows permanently tattooed, and the colour of the ink perfectly matched her natural hair, blending softly into her complexion. Meeting her reminded me how well people with BFRBs are able to hide the visible effects of their disorders, and the way that people learn to manage their BFRB body. In this first chapter I will explore the different methods used by women and men to conceal the physical effects of hair pulling and skin picking. I refer to these methods as “techniques of concealment”.

Through examples of women and men's efforts to remain hidden, I will show how different techniques demonstrate the impact of BFRBs on sociality, where fear of revealing the BFRB body prevents people from certain social interactions. Maintaining techniques of concealment is an ongoing process, that often makes people feel isolated. The ongoing effort to hide the presence of a BFRB makes people feel “abnormal” and they long for “normal”, mundane experiences. Woven throughout this discussion is the theme of temporality, in relation to the time spent practicing techniques of concealment over many years; expressed in certain life course events where people hoped to overcome their behaviour; and also through inevitable changes to the way people perceive their BFRB bodies and sense of self over time. Among the diverse experiences of my interlocutors I unpack the role of intersectionality, highlighting the way that gender, sexuality and race influence the

forms that techniques of concealment take and to whom they are accessible. Through examining the BFRB body, and people's attempts to conceal it, it becomes clear that the bodily damage caused by BFRBs can be intensely embarrassing. However, by considering the embodiment of hair pulling and skin picking, and the complex sensory elements that they involve, I argue that the risk of being revealed goes beyond simply the visible effects of a BFRB.

### **Techniques of Concealment**

Throughout my fieldwork, people often described the ways that the visible effects of BFRBs affected their lives. For all of my interlocutors, it was important to conceal the existence of a BFRB by covering hair loss or scars on their bodies, and to avoid performing pulling or picking behaviours in public places in order to keep it a secret. This involved various techniques of concealment that people used to keep their BFRB hidden - intense practices that became a burden in everyday life. This process of hiding can prevent people from experiencing what they consider "normal" daily activities and interactions, and therefore the BFRB body becomes a barrier to sociality. Thus, techniques of concealment play an important role in the everyday management of the BFRB body. The idea stems from Mauss' (1973) classic concept of "techniques of the body" which considers the way that people move their bodies in various activities across societies (such as swimming or walking), and how this movement can create embodied habits, or *habitus*. Importantly, Mauss describes how these techniques are socially learned and imitated over time between different people, and are therefore not universal. Crossley (2005) has acknowledged the absence of the self in Mauss' discussion of these techniques, and as such he has developed the notion of "reflexive body techniques". For Crossley, reflexive body techniques capture the way that people modify and manage their bodies in everyday, mundane ways, and how these practices can alter the way the self is perceived. He says: "[reflexive body techniques] can have a ritual function, serving to symbolically and 'magically' mark the transition of the self from one situation to another" (Crossley 2005: 14). Crossley also mentions the

collective nature of reflexive body techniques, commenting that this “body work” can be performed by more than one “embodied agent”, such as a hairdresser (2015: 9-10). Building on both Mauss and Crossley, I have expanded the notion of techniques of the body to account for the ways that people with BFRBs use different techniques to manage their bodies in order to remain secret. The notion of techniques of concealment addresses the importance of secrecy and stigma, focussing on the reasons why people feel they need to conceal evidence of their behaviour, as well as the methods they use to do this. As we will see, these techniques of concealment can help to reduce the possibilities of stigma from others, but they also act as a barrier to sociality, affecting the way people move and interact in the world around them.

Due to the diverse nature of BFRBs, their location and pattern on the body, techniques of concealment differ depending on the body part needing to be concealed. As the majority of my interlocutors had been dealing with trich or derma since childhood or adolescence, these techniques had become well-practiced. Particular hair styling and use of accessories were common for my interlocutors, and each person had their own preference and techniques to covering hair loss in different ways - including the use of hair bands, scarves, glasses, wigs and sprays.<sup>6</sup> In the examples that follow we will see how people have both positive and negative feelings towards the function of these techniques of concealment: primarily they are a benefit as they allow the BFRB body to remain secret; but this can hinder social interaction and the forming of relationships. Techniques of concealment can act as a physical barrier to target areas, preventing people from pulling or picking in public; but additionally they become a daily reminder of how their disorder restricts “normal life”.

For Denise, techniques of concealment were both essential, and a huge burden. We met for the first time in October 2015 when I travelled to her meet her in the small town where she lived, an hour outside of London. We had planned to have dinner for

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<sup>6</sup> These products are known as “scalp make-up” and are essentially coloured hair sprays designed to fill in gaps of baldness on the head, one example is a brand called “Fullmore”.

our first meeting and interview. I arrived at the train station in the early evening where she picked me up in her car, having just finished work. We drove together to the restaurant and chatted about my project so far. She was excited to finally meet me, and admitted she did not talk often about her hair pulling. Knowing that Denise's trichotillomania affected her eyelashes and eyebrows, as I sat close to her in the passenger's seat I avoided making too much eye contact, but noticed her heavy eye make-up and pencilled-in eyebrows. She was not yet thirty, was soon to be married, and talked about the stress of wedding plans. As our meal progressed and we talked more about her intimate experiences with trichotillomania, Denise told me that she never went to bed without her make up on. She had been living with her fiancé for several years, and he knew about her "problem", but it was rarely discussed and she said she would be "horrified" if he ever saw her without her make-up. When I asked why, she said: "He says he doesn't mind, but there's no way he could love this face". As we talked more about her need to sleep with make-up on, and her extensive research into durable products to make this possible, she told me more about her worries. "It's not just that I don't want him to see me, but, I guess it's anyone. I mean sometimes I think about my mum, who is in her seventies, I think what if something awful happened to her in the middle of the night, and I got called out suddenly to help her? Or, I mean what if there was a fire and I had to escape? I just think about those scenarios and the last thing I'd want to be worried about it whether I have my eyeliner on or not!"

The level of thought given to techniques of concealment was expressed by other women, who spent large amounts of time searching for the right products, watching online tutorials to learn how to draw eyebrows on properly, practicing these techniques in order to leave the house feeling comfortable. In one of our Edinburgh support group meetings in autumn of 2016, these techniques of concealment were discussed. One woman described the itchy-ness of her wig when the weather was warm, another said her contact lenses and eyeliner mixed together to create an uncomfortable sensation on her eyelids. Someone else joined in and said: "Yeah, like



when I take my wig off at the end of the night it's so satisfying, like that feeling of taking off a bra!" This comment was followed by laughter, and the others in the room agreed that these daily practices of hiding came with a feeling of constraint and discomfort. As well as the process of applying cosmetics, wearing wigs or styling hair to keep damage invisible, the worry about people seeing through these practices was constant, and occupied a great deal of time and energy. For those who relied on make-up, they found themselves checking regularly in mirrors and windows to ensure it was properly applied throughout the day. Despite the anxieties surrounding the use of cosmetics, and the constant effort necessary to ensure skin and hair is maintained, these techniques were of course highly valued and praised, as they allowed people to feel "normal". The increasing diversity and quality of make-up and hair products meant that people were able to adopt new techniques that helped their false hair or lashes to appear more "natural" and "realistic". In one support group a woman said: "Thank God that fake eyebrows are back in fashion!". People did not feel negatively about the quality or efficacy of these products, it was the feeling of constant necessity of their use that became a burden. Women were often caught between feeling thankful for having make-up to help cover their damage, but also wished they could be more open about its use. As one woman in a TLC workshop said: "I'm so *tired* of hiding and having conversations with people about why I wear so much make up. I feel like these are disorders of people hiding".

Returning to Mauss, techniques of concealment, like techniques of the body involve *movement*. The habitus involved in these techniques of concealment, the way they are repeated, and the way people enact this body work on themselves, becomes learned and repeated, allowing them to behave and move in the world in ways that are acceptable and "normal". This reinforces what Goffman has said about stigma and how people attempt to gain acceptance by covering "blemishes of individual character" (1968: 20). Green (2009) has suggested that we are moving "beyond stigma", arguing that the introduction of new technologies allows people to conceal the effects of illness better than ever before, using the example of anti-retroviral

treatments for HIV/AIDS. For BFRBs, techniques of concealment certainly do offer people a level of acceptance, and in many ways they allow people to interact in the world like they would otherwise be ashamed to do. The use of make-up is a technique that helps women to conceal, and thus avoid stigma from other people. But we have also seen that techniques of concealment also *prevent* sociality, as the fear of being revealed remains, and certain social situations are avoided due to the chances of techniques of concealment failing – like make-up being washed away in the rain. Shame is still present then, and reinforces the experiences of stigma from people towards themselves.

We can see parallels here with Wool's (2015) work, which describes how past memories can shape the way people move in the world after experiences of trauma. In her ethnography of soldiers living with PTSD in the United States, she demonstrates how certain experiences of war change the way the body feels, and alters perception in terms of heightened sensory awareness. Wool explores the relationship between how people move and how people see, showing how "moving and seeing are imbricated" (2015: 141). She describes the way one of her interlocutors scans public spaces, sensing the physical space and the people within it, and through this scanning potential risks become newly apparent, moving into view. Analysing the experience of her interlocutor Wool explains,

In her own way she points to the intimacy between becoming, becoming visible, and coming to see... She sees and feels the world as it is, and the world is as she sees and feels it. It cannot be otherwise. She feels that this world is a different one from the one she knew before Iraq, but also that it is she, and her vision, that have changed: 'It changes you, it changes the way you see' (Wool 2015: 143).

In the techniques of concealment that I have described, we can see the way that people's bodies learn to conceal in ways that become normalised, repetitive and part of the everyday. But through these techniques, the things that people cannot do, become more obvious. The techniques, also affect the way that people see

themselves, with heightened senses in certain situations that focus in on the aspects of the self that to others would likely go unnoticed. Techniques of concealment bring the BFRB body into view for those who attempt to hide it, revealing it's "abnormality" even more clearly, and the fear of being revealed changes the way they move in the world around them.

For people living with BFRBs, hiding is important, and fear of being revealed is real. The question of to whom BFRB bodies are revealed, and at what point in time, is discussed in Chapter Two in relation to family members; but in the next section, I expand on experiences of stigma that affect the perceived risks of revealing BFRB bodies.

### **Stigma and Risk of BFRB Bodies**

Denise's concern was not only about being in an emergency situation. It was a fear of being in an emergency situation *and her secret being revealed*. For this reason, Denise took the time each morning to apply various layers of eye make-up and false lashes, not only to make her hair loss invisible, but to make her lashes and eyebrows seem realistic and thereby avoid comments or suspicion from others. The fear of being revealed is connected to a fear of stigma - both the imagination of judgment from others, and shame that linked to negative perceptions of the self. For fifteen-year-old Megan, who I interviewed at her therapist's office in Washington, DC, this relationship between the BFRB body and stigma was made clear.

Megan started pulling at age twelve, in seventh grade. She was fifteen at the time of our interview and had been going to BTC for about three years. She sat far away from me with her arms tightly closed, appearing very small as she slouched in the armchair that surrounded her slight frame. She wore a bright tie-dye t-shirt and matching headband around the front of her head, covering much of her hair. Her face was

awkwardly painted with make-up, with messy dark eyeliner around her eyelids and brows. She told me about the feeling of being stared at:

When I first started this in seventh grade people used to just *stare*, and I *hated it*. I hated it when people stared at me. It made me feel so targeted. I would just cry instantly, I didn't like it, I felt like I was being stared at all the time. I felt different. I mean now in high school, it's meant to be the important time of your life, but it's hard for me to fit in because I feel different... and there are some days when I don't wanna hide it. You know, I just wanna go to school, I don't wanna wear make-up, I don't wanna wear headbands, I just wanna show myself, and then I'll get scared, and those voices tell you 'people will make fun of you, people will judge you' [Megan's emphasis].

Since that time, Megan has developed her techniques of concealment to try and change how people see her, and through this she is able to hide her BFRB to some extent. But her techniques of concealment do not change the way she sees herself:

It's hard to feel good about yourself when you feel very upset because I can't have my hair like other girls, or I can't wear make-up like other girls, and I used to *love* styling my hair, and I feel like I took that away, I blamed it all on myself. I feel like I'm doing the pulling, no one else is, and it's really just my fault. It really killed me inside because it hurt to see myself not be able to feel good about myself... I lost that self-confidence. If I could say about my self-confidence now, it's probably like a 1 out of 10 [Megan's emphasis].

For Megan, techniques of concealment only help to reduce the enacted stigma by others, but the felt stigma towards herself continues through feelings of blame, which in turn affect her self-confidence. She later told me that this was caused by voices inside her head:

Those voices in your head that tell you like 'you're not good enough'...it really hurts your self-esteem and self-confidence for yourself, and it definitely hurts me a lot, because you know I'm trying to feel good about myself but those little voices just totally kill it.

We see that despite her use of techniques of concealment, Megan's perception of self is severely altered by her hair pulling. Goffman has mentioned the way that people attempt to gain acceptance through changing the physical appearance of the body and concealing their stigmatising attributes. He says, this "quest" of trying to conceal the body highlights the "extremes to which the stigmatized can be willing to go, and hence the painfulness of the situation that leads them to these extremes" (1968: 20). Megan's description of the voices inside her head reveal the way that shame is embodied, and involves a communication between mind, body and self. Goffman's (1968) work on stigma has highlighted the role of the body, noting that individuals can be "disqualified from full social acceptance because of an undesired bodily differentness" (Goffman 1968:14); but in his work, the relationship between the body and mind is overlooked, and he also says very little about shame. Here we can see that stigma does not just concern other people, or "normals" as Goffman calls them, the experience of feeling stigmatised is often not dependent on the reactions from other people, but the intense shame that is internalised through fear of stigma, affects the way people feel about their self. Megan shows this process by describing the conflicting relationship between her body, her mind and her self.

The role of the body in attempts to remain secret has been described by Hardon & Posel (2012), who argue that secrecy can be understood as a "social practice by emphasising the centrality of the body and the experience of embodiment in the making and unmaking of secrets. To keep something secret requires a compliant body" (Hardon & Posel 2012: 3). Arguably, the "compliant body" that helps to conceal secrets is also determined by certain context-specific beauty norms. So too are techniques of concealment, and they therefore reveal the ways that certain aspects of identity influences choices of how to conceal the BFRB body, and how their bodies are perceived. As I have shown, the cosmetic practices mentioned above - while helping people to positively blend into daily life without their BFRB being revealed - sometimes led to accusations from others. For some women, the intense focus and effort involved in these cosmetic cover-ups had been noticed by family members or friends, and was

sometimes wrongly assumed to indicate “vanity”. Some of my informants mentioned that the time they spent in their bathrooms each morning, or their constant checking of themselves in mirrors, was considered to be some kind of self-indulgence – a reading that stands sharply at odds with reality, where people simply wanted to be appear “normal” or unnoticed. While shame and secrecy has been explored by other scholars, often lacking is a discussion on how these methods of hiding are perceived by others. Warin (2010) has shown how people living with anorexia use bodily techniques to continue with secret practices of not-eating. In her ethnography she describes the way that these “tactics of concealment” are interpreted by caregivers, and called “anorexic tricks” (2010: 85). Warin describes how these tricks act as a way of relating to others with the diagnosis. The secrecy of anorexic behaviour could be understood then as a technique of the body, as Mauss describes it, which is learned and imitated through social connections. Warin argues that the “power of secrecy lies not only in what it conceals – trying to hide practices from staff, friends and family, for instance – but also in what it reveals and creates” (2010: 86). Techniques of concealment can therefore become powerful tools of controlling how and when the BFRB body is revealed, and to whom.

Solina, a twenty-year-old Romanian woman living in Scotland, had mixed feelings about whether to reveal or conceal. She described the way she had become reliant on make-up to cover the skin picking scars on her face, and how she worried that the heavy application of foundation had become a clue that she might be “hiding something”, since she never wore any other make-up. She said he actually “hated” using make-up, and preferred “natural” beauty, so her closest friends and family were confused as to why she wore foundation every day. Here we see that the process of concealing can also highlight the very things that are trying to be hidden, creating a struggle that needs to be negotiated in different social situations. For example, Nicole described the mundane activities that she felt unable to enjoy or participate in, like swimming, or going out in the rain. Certain activities were mentioned regularly as difficult for people to engage in for fear of revealing their hair loss or scars: swimming,

going to the hairdresser's, sitting close to people on public transport, going out in the rain or wind, and becoming intimate with potential partners. While these activities were highlighted as key examples, people described their constant worries about keeping their hair loss hidden, which were relentless and exhausting. This affected strangers on the bus and colleagues at work, but for some it also extended into the household, which made "normal" life feel even more challenging. Like Denise, other women would sleep with their make-up on with new partners, or would set alarms to wake up earlier to make sure they allowed enough time to continue their daily routines. This added time and effort acted as a reminder of their difference to other people. One woman said: "I can't just get out of bed in the morning and throw on any old thing, it takes *forever* to get ready." The belief that female beauty practices are effortless and quick has been highlighted by feminist scholars as an illusion that reinforces assumptions of "natural femininity" (Toerien & Wilkinson 2003) and is clearly not representative of everyday life. However, for people with BFRBs, the idea of "natural femininity" or "beauty" is connected to the desire to show their face or skin without cosmetics, and the fact that they feel they cannot let their damaged hair or skin be visible - preventing them from feeling "normal" in comparison to other people. This was heightened for people by advertising, and images of other women who had "perfect" hair or skin. Again, the reality of this as a model of female beauty is flawed, but for people living with BFRBs this is an example of how unattainable such "norms" will ever be.

The differences between men and women in these techniques are important. Several of my female interlocutors found that shaving their heads was the best way to "deal with" their hair pulling, although the public reactions to this often increased the sense of shame and stigma. For other women, the option for them keep their hair short was not considered as "easy" and it was they assumed it was for men. However, my conversations with men suggested that choosing a hairstyle that was both socially acceptable and helped to hide their hair loss was far from easy. Morris, a twenty-two-year-old student from Oxford, had been pulling out his hair since he was a child. As a

young boy, he kept his hair short to try and hide the bald spots, but now he was a young man, he had decided that allowing his hair to grow long and curly was the best way to hide the fact that one side was thinner than the other. Morris described his constant worry about people noticing his “shabby”, unbalanced haircut, and said he struggled to appear smart and professional in certain scenarios. Olly, an older Scottish man who I met on several occasions near Stirling, also found that sticking to a shorter hair style allowed his hair loss to blend in and look unsuspecting, but complained that he was unable to grow a beard as he knew he would end up pulling it out. Jack had struggled over the years to hide the evidence of his thinning eyebrows, and has found solace in wearing thick-rimmed glasses make his hair loss less noticeable unless people are very close to him. He felt that wearing make-up was not a viable option as it would draw unwanted attention and would raise questions about his sexuality. Here we see that while techniques of concealment reveal gendered beauty norms, the intersection between gender and sexuality also plays an important role. This was also highlighted by Lou, who felt confident shaving her head since she identified as a gay woman, although some straight women worried that shorter hair styles would give the impression that they were gay.

Beauty norms in relation to race are also revealed through people’s techniques of concealment. Robyn, a Black woman from London whom I met one sunny October day on the city’s Southbank helped me to understand the racialised experiences of hiding. Robyn was around six feet tall, and wore her hair in tight dreadlocks. She was in her late thirties and a mother of a young boy and girl, whom she mentioned frequently during our meeting. Robyn told me how her identity as a Black woman had helped her to reduce her hair pulling, as she was able to wear her hair in dreads without anyone noticing anything out of the ordinary. She implied that dreadlocks on a white person would raise questions. Robyn said that her hair pulling was never really a “big issue” as she was always able to keep it concealed, and she is now able to control her hair pulling through the dreadlocks, which block her ability to pull from certain areas of her scalp. Robyn reflected on her childhood and adolescence, when she tried various hair



styles, including weaves and wigs which she said she “hated”, because they felt “heavy” and “itchy”. Despite not using them anymore, she still enjoys visiting the Black hair salons in London and looking at “all the products”. But she made a point of saying she wants to keep her six-year-old daughter away from them, as she is well aware of the pressure that Black women face with their hair. She told me that her daughter was recently excluded from another child’s birthday party, being told it was because her hair was “too curly”, and she had since asked Robyn if she could have her hair straightened. Robyn’s response was to regularly make a point of telling her daughter that her natural hair is “beautiful”, but this caused her younger son to ask: “Mummy, is my hair not beautiful?” Robyn said to me, “I felt awful. Why don’t we talk about beauty to our sons?”

Robyn’s realisation that she was more inclined to worry about her daughters’ overall beauty than her son’s is a reminder of the unbalanced cultural value that exists between men and women’s bodies. Much more can be said in relation to the social influence of beauty norms in men and women, and I will return to this topic in Chapter Three. For now, it is important to highlight the role of gender, sexuality and race as factors that shape techniques of concealment and that influence people’s relationships to their BFRB body. Robyn’s story also speaks to the theme of temporality, as she considers her own life history alongside that of her children, attempting to change the way that her son and daughter experience the social pressures of body image. In the next section, I delve further into these temporalities, showing how techniques of concealment change throughout the life course.

### **Concealing Over Time**

In many ways, techniques of concealment helped to reduce the shame associated with the visible effects of BFRBs. By wearing a wig, or covering hair loss and scars with make-up, people were able to feel more comfortable and confident in public, and this improved their self-esteem. But as I mentioned above, these practices also take time,

and required ongoing maintenance, and acted as a reminder that “normal” everyday activities were less achievable. Ultimately, people wished they didn’t *have* to use them, and longed for the “freedom” to live without them. Here we see a paradox of “normalcy”, whereby techniques of the body allow people to feel normal by concealing the BFRB body, but they long to achieve authentic “normality” which is imagined through overcoming their BFRB. This connects back to Goffman’s work on stigma, which is missing any discussion on how stigma and perception of self in comparison to “normals” is sought out over time. Like Goffman says, the efforts that people go to to conceal their stigmatisation reveal the extent of stigmatisation, and yet time does not come into this discussion as a factor. I argue that the length of time practicing techniques of concealment is an important aspect of stigma experiences, and further alters perceptions of the self.

For Nicole, the longing for normalcy was reflected in some mundane activities that her trichotillomania prevented her from enjoying, like swimming. As she explained:

And it’s funny the joy that you feel with the little things... like going out in the rain, or standing in the shower and just letting the full pulse of the water go on my face, because otherwise I have to avoid [it]... But swimming, I remember one time I had just gotten my eyebrows tattooed, I had a full complement of eyelashes [laughs and claps her hands gleefully] and I went underwater for the first time in *years*, and it felt so damn good, I just spent most of the time underwater... And it was just so wonderful, I’ll never forget that feeling of freedom, *freedom* to do what other people do and take for granted [Nicole’s emphasis].

Techniques of concealment here become attempts to transform the abnormal BFRB body into a “normal” body. These techniques are productive, they alter bodies and temporarily change people’s perceptions of the body and the way the body is able to move in the world. But their constant use over time creates challenges.

In Nicole’s example, tattooing her eyebrows became a long-term technique of concealment, but for others techniques like make-up and wigs were much more

temporary and they were unable to achieve the same freedom that she describes. Of these everyday activities that Nicole describes, like taking a shower or going out in the rain, were made meaningful due to their “every-day-ness”, thus implying a sense of normalcy. Other activities were made meaningful to different people at different stages of their life course. For example, swimming was for many people a significant activity that they missed even more while on holiday. But swimming was also considered to be a fundamental skill and playtime activity in childhood that might be lost due to the anxiety surrounding BFRBs. The importance of swimming as an activity for children was made evident during the TLC conferences, when the organisers always ensured that there was a scheduled swimming session for kids. Parents described to me the emotional experience of watching their child swimming and enjoying themselves with other children “just like them” without having to worry about who was looking.

The idea of swimming as a hobby important to “normal childhood”, and the feeling that BFRB children are unable to achieve this, highlights the way that BFRBs are in many ways “disabling”, although few of my interlocutors would described themselves as having a “disability”. Disability is often measured in relation to the common understanding of a “good quality of life”, which is implied as subjective well-being and general satisfaction with life (Goode 1994). Recent work has challenged the idea that people living with disabilities experience poor quality of life (Albrecht & Devlieger 1999), causing us to reflect on the social and medical models of disability (Shakespeare 2017). These models of disability compare approaches to what people with disabilities ought to be able to do in their lives. The medical model suggests that disability should be improved upon for people to live a more “able-bodied” life, while the social model argues that society has a responsibility to be more inclusive and therefore allow different people’s abilities and needs to co-exist. When considering what we mean by “quality of life”, the social model of disability would argue that people living with disabilities can achieve a high life quality despite differences in ability. However, the medical model still influences much of Euro-American notions of health, and in

particular disability services are often framed around helping disabled people live “normal” lives (Bumiller 2008). The idea of being “normal” in terms of appearance is clearly linked to gendered beauty norms which shape the techniques of concealment described above. But like the social model of disability suggests, people attempt to question the social factors that shape experiences of stigma. In many ways this idea of “normal” is being challenged in the BFRB community, and I will return to this in Chapter Three and Chapter Four.

In the examples I have given above, we can see how people with BFRBs aspire to live “normal” lives, measured in many ways by participation in everyday activities. Yet at the same time, the children who go swimming without their techniques of concealment enjoy doing so in the safety of their surroundings, with the encouragement of people who share their embodied experience. Evident also in the work of Albrecht & Devlieger (1999), quality of life and the ability to overcome shame from living with a disability is often dependent on one’s sense of self in relation to one’s body, but also on the harmonious relationships found in support networks. I argue that techniques of concealment are important to people with BFRBs due to the embodied shame of living with these behaviours, which creates a conflicted relationship between the self and the body. As this thesis progresses, I develop my argument to demonstrate how the BFRB community can help people to overcome feelings of shame, and in turn positively impact the perception of self and view of the BFRB body.

Living a “normal life” not only involves mundane activities like swimming. For a number of adult women, important life course milestones were treated as goals for overcoming their BFRB. Significant birthdays were frequently mentioned, as were graduations, weddings and the birth of children. Catherine, a Scottish woman in her fifties, mentioned these milestones during our first meeting:

You have all the sort of milestones in your life, you think: ‘before I get married, I’ll definitely grow myself a full head of hair’, ignoring the fact that

it's a very stressful time of life and you're going to pull *more* hair. And then: 'by the time my first child is born I'll have stopped, by the time my *second* child is born I'll have stopped, by the time my *third* child is born I will have stopped!' And it just doesn't happen [Catherine's emphasis].

A similar description of milestones was relayed to me by Annie, who had recently had the Intralace System fitted when we met for coffee in a Sheffield shopping mall. She said: "I want to try and have my own hair when I'm thirty, so I'm nearly twenty-seven now. I always said to myself I'll have my own hair on my wedding day, and there's always been goals like that; by the time the time I leave school, by the time I have my first job - by the time I'm dead I'll have my own hair! [laughs]". A few months before our meeting, Annie's husband had paid for her hair system as a wedding gift for her. After explaining this to me she said: "So I always said to myself I'd have my own hair [by my wedding], but I got the next best thing".

Catherine felt that her hair and her life course goals never matched up, but Annie was happy to have "the next best thing". The dream of having their "own hair" or a "full head of hair" reiterates the importance of bodies in life course experiences, particularly for women. While the men I interviewed were less likely to mention these same milestones, during an interview with a hypnotherapist from London, she told me that she often had enquiries from men with trichotillomania just before important life moments, like the birth of their first child, or their wedding. While I am unable to speak to male experiences to the same degree, it is important to acknowledge that physical appearance in the life course does not just influence female experiences of BFRBs. Catherine and Annie share the experience of having their hair goals unfulfilled in terms of having their "own hair"; but as a younger woman, Annie remains set on her goal for the future, while Catherine has a level of ambivalence in her older age. Towards the end of this chapter I will return to this discussion to show how time can shape ideas of recovery and acceptance.

So far I have shown how the visible effects of BFRBs, and attempts to hide them prevent one from doing "normal" daily things and enjoying special milestones. Having

considered the efforts that people go to in order to keep the BFRB body hidden, the next section will unpack the feelings of shame associated with BFRBs, and the fears of what might be revealed through uncovering the BFRB body.

## Embodied Shame

Much of this chapter has described efforts to conceal the physical effects of BFRBs on the body. We saw in Denise's example - especially when she said "no one could love this face" the way that people see their BFRB bodies is usually negative, and involves feeling ugly and often unworthy of love. In addition, hair loss and scars were considered embarrassing and shameful, and not simply due to the visible marks in themselves. Instead, the anxiety of revealing the BFRB body is connected to the fear of admitting the cause of this visible damage. As Chandler has described in relation to the self-injured body: "Perhaps the physical wounds have *some* meaning then—they cannot be fully dismissed even where they should not be focused on excessively" (Chandler 2016: 28). In a similar sense, the visible effects of BFRBs have important meanings that I do not wish to undermine, but it is these visible effects that were often the main focus of medical professionals when some of my interlocutors attempted to seek help. In these encounters, several people reported being asked to reveal their bodily damage. I had a similar experience; when I was asked to reveal my own hair loss to a general practitioner at the age of twenty, her response was "it's not that bad, it could be a lot worse". While visibility is important to BFRB experiences, and most certainly affects self-esteem, the embodied experience of BFRBs is a great deal more complicated than just what is visible on the body's surface.

"For me it's not about the sensation", Joy said quickly, as she told me about the hair extensions she had been using to help cover the thinning hair behind her ears. She had been describing the way the extensions had been useful for her as she could pull them out instead. Although they saved her hair, the extensions were becoming costly to replace every six weeks at Beverley's salon. I was intrigued at this lack of sensation,

and I heard her say it again to the hair stylist when we attended the salon together in Edinburgh. It interested me that she did not gain sensory rewards from hair pulling, which was unlike anyone else I had spoken to. Following the appointment, we decided to go for a coffee nearby. We sat in a quiet corner, and she asked me about the support group that I had started in Edinburgh. I told her there was a woman who comes to the group who had recently managed to stop pulling completely, and suggested she come to the next meeting to meet her and the others. I said: "It's quite remarkable actually, because she has been pulling for most of her life, she also eats the hair which can be quite serious". Joy looked up suddenly, and abruptly burst out: "That's what I do". She began to get flustered and seemed embarrassed, and told me she had never said that out loud to anyone before. She said "God it's so weird isn't it! It's not *normal*!" I reached out to touch her arm, and tried to reassure her that it was actually quite common and she shouldn't feel embarrassed. She talked about it for a while and then said: "You know I actually feel like a weight has been lifted to tell you that".

For Joy, the ritual that she goes through with her hair, which involves ingesting the hair strands after they have been pulled, is so private that she has been unable to share this information with anyone over the years. Her inexplicable urge is both confusing and frightening, and has caused her to withhold this information from healthcare providers and family members, despite knowing that she could be causing herself physical harm.<sup>7</sup> Joy did experience a sensory reward in her hair pulling ritual, but it was not one she felt able to share with anyone, and therefore she kept it a secret. While she was able to visit the specialist salon and reveal her hair loss to the staff during her treatments, and able to admit she was pulling it out, she was unable to reveal the fact that she would eat her hair.

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<sup>7</sup> The name for pulling out hair and ingesting it is "trichophagia". The physiological result of eating hair can have cause "trichobezoars" or hair balls, to form in the stomach, and can cause death if untreated (Grant & Odlaug 2008, Lynch, Feola & Guenther 2003). Trichophagia is featured more regularly than trichotillomania in the press, often in sensationalist articles, which I discuss in more detail in Chapter Three.

For many others that I spoke to, the rituals that they felt they had to go through each time they pulled hairs or picked their skin were often considered intimate and private, and were rarely discussed unless they were in a safe and private environment like a support group, or in online Facebook groups among other people who suffered from BFRBs. However, it is through these intimate rituals that we begin to comprehend the deep embodiment that is involved in the lived experiences of BFRBs, and the extent to which secrecy becomes a way of life. This feeling of abnormality comes from the unusual nature of these disorders, which begin suddenly and are difficult to stop; but it is also influenced by the lack of public awareness about BFRBs, which means that people often begin thinking they are alone in their experience, reaffirming the idea of being a “freak”. This was frequently described to me when people reflected their earlier years, when pulling or picking began: “I thought I was the only one in the world that does this *crazy* thing”. Feeling like a “freak” then, creates feelings of embarrassment and deep shame, not only for doing a behaviour that is unusual, but for being unable to understand *why* it was happening and *how* to stop. The sudden urges and complex sensory rituals that make people feel out of control. And while shame influences the desire to make BFRBs invisible, confusion and lack of understanding influence experiences of shame.

People with trichotillomania undertake a variety of rituals that involve similar sensory rewards, but unlike the case of trichophagia, these different rituals do not lead to alternative labels. These rituals included, searching for that certain hair: one that feels more “crinkly” or curly than the rest, or different in colour, and therefore should be removed – removing many more in the process. People mentioned that these hairs felt different to the rest once they were pulled, and they would usually spend time examining the hair, running it through their fingers, sometimes across their lips, or through their teeth. Some people described the sensation of hearing a “pop” when the hair was pulled, and for most, there was a fascination with the white “bulb” at the end of the hair which would either be detached from the hair itself, or sometimes eaten. What people did with the hairs once they were pulled also varied, including



tying them in knots, breaking them into pieces, or ingesting them; but they were rarely kept - for most people, the hairs were then discarded. At this point, people often described feeling guilty or disgusted at what they were doing, and wanting to get the hair as far from them as possible, usually throwing it on the floor or hiding it from family members. People described not knowing *why* they did these rituals, but that the sudden urge to complete these actions in this order was uncontrollable and inexplicable. This lack of understanding of their bodily urges made them feel completely out of control, as if something else was taking over their bodies. The hair loss that resulted from these uncontrollable, repetitive urges was less of an issue, and some women told hairdressers that they had alopecia or were even going through chemotherapy to avoid admitting they were pulling their hair out. I will return to this idea in Chapter Three when I discuss the way media representations reinforce the stigma of female hair loss.

Skin picking also involved sensory rituals, where people described the feeling that there was something “under the skin” that needed to be removed, or a desire to make the skin “smooth” rather than “bumpy”. As I will develop below, these rituals have important temporal qualities, including getting lost in the “zone” and losing sense of time.

### **“A zoned-out sense of calm”**

The state that people entered while pulling and picking was often described as a “trance”, which could sometimes last for hours. This was case for people who experienced pulling subconsciously - referred to by clinicians as “automatic” pullers/pickers - who sometimes awoke from this trance to find hundreds of hairs in front of them that they did not realise they had pulled. But this trance-like state was also described by people who pulled and picked consciously (“focused” pullers/pickers), who would sometimes escape to the bathroom or bedroom to get into this “zone”. The passing of time during a trance like this was frequently mentioned, as one of the most frustrating aspects of BFRBs. People said they found it

hard to deal with the amount of time that they wasted pulling or picking, knowing that they had other things they should be doing, but feeling unable to break out of the “trance”. Rose told me during our first meeting in a London café that sometimes she would be driving and pulling her hair at the same time, with both hands to her head, not paying attention to the road and waiting as long as possible to bring her hands back down to the steering wheel. She described this to me as “terrifying” and she was well aware how dangerous it was, and yet she felt unable to pull her hands away from her hair. Others describe this trance in terms of “zoning out” from negative situations or feelings, like Liz whose personal journey with skin picking featured in a recent publication by The Body Dysmorphic Foundation,

Skin picking was, for me, from a young age, a way to release tension in my body, to block out emotions and hit a zoned-out sense of calm... I experienced intense physical anxiety, followed by guilt and shame over the things I was doing that caused harm to my own body, yet felt no control over it or any ability to stop (Liz Atkin, in Schnackenberg & Petro 2016: 234-235).

Schüll’s (2012) book on compulsive gambling in Las Vegas also describes the “zone” that people enter while gambling, and the ways that both time and awareness of the outside world can pass by. Similarly, Lavis (2015) presents the experiences of people living with anorexia who described the way their thoughts about eating and not eating allowed them to “zone out” of the real world; making anorexia a “safe space” for them to “zone into”. The emotions involved in the “zone” were often important, and people often used this time to escape from negative feelings or thoughts, comparable to purging. But “the zone” could also be entered subconsciously, especially for “automatic” pullers and pickers. For those who were more “focused” it would lead people into the spaces where people disappear to pick or pull, usually in private bathrooms or bedrooms, with mirrors being a strong trigger for entering the zone. People often described to me the way they “got lost” in mirrors, struggling to walk past the bathroom without being tempted to go looking for skin imperfections, or hairs out of place. Mirrors acted as technologies for seeing, perfecting, and destroying the

body; windows into negative self-esteem. The use of mirrors encouraged the obsessive nature of their behaviour, and allowed people to see imperfections more closely, adding to the intense and overwhelming experience of being “in the zone”. Lauren said, “Mirrors became tantalizing, almost fun-house-esque. My body seemed to walk itself over to them no matter how much my internal voice knew better”. I began to notice mirrors more during my fieldwork, and in the spaces through which I moved. In the waiting room bathroom of the Behaviour Therapy Center in Washington, DC I was surprised to see a Hollywood-style mirror, with uniformed bare lightbulbs protruding from the frame. When I stood in front of it, every pore on my face was brightly lit, every tiny hair visible. Considering the large number of people with BFRBs who passed through this space, and despite being home to several BFRB experts, this suggested to me that the Center did not take seriously the ways that mirrors can be triggering for people. Here we see that the material surroundings of a space can influence the experience of being in the zone. This attention to spatial structure echoes what Schüll (2012) has described in relation to the architectural design of casinos. She argues that way the physical environment of the casino has been built, encourages the embodied experiences of the zone, and feeds addictive behaviour. While the triggering mirror in the BTC appeared to be placed accidentally, other mirrors that I noticed in my field site seemed to encourage the negative self-perception that is linked to BFRB experiences of seeing the self. This was especially clear to me on my first visit to Beverley’s London salon when I sat across from her in her office.

Beverley is a short and shapely woman, in her early sixties, although she looks younger. She was always well-dressed in smart, designer clothing, and wore a selection of jewellery that clinked as she waved her arms enthusiastically while she talked. Her hair was long, straight, and a warm shade of blonde. Her teeth were sparkingly white, shining behind her red painted lips and tanned skin. She is an affectionate person, and always greeted me with a hug. On my first visit to the salon, she invited me into her office, where I was instructed to sit on the client side of her desk. Behind her stood an

enormous mirror. Facing Beverley, who had a face full of make-up, looking as close to a Barbie doll as she could for her age, I was also faced with the image of myself, sitting beside her in the shiny mirror. When I arrived, she had told me she “loved” my outfit (a pair of jeans, black trainers, a short-sleeved white shirt, a multi-coloured plastic necklace, my hair messily curly), but I began to feel insecure and wished I had made more effort with my appearance. This interaction left me feeling deeply uncomfortable with the way I looked. I found myself thinking carefully about what I wore and how I styled my hair on future visits to meet Beverley, and the memory of seeing myself in that mirror parallel to her stayed with me.

The vulnerability and insecurity that I felt in myself when comparing myself to Beverley is likely to be how other women felt when they attended a consultation with her. BFRBs can alter the perception of self, and this perception of self, reflected in the mirror can trigger BFRB behaviours and entering “the zone”. I will return to this discussion of mirrors in Chapter Five, where I argue that these triggering objects can become tools for recovery. Overall, the temptation to become drawn into the zone, as well as the urges associated with this “zone” make it difficult to break these trances - a difficulty often described through the language of addiction.

### **“I feel like I need to go to rehab”**

Dhaya and I were sitting in her living room at home on the outskirts of London, after having picked up her children from school. She was annoyed and animated after an encounter earlier that day with a woman in the school playground. Dhaya had been taking part in a sponsored race as part of BFRB Awareness Week,<sup>8</sup> raising money for TLC. Dhaya has done an increasing amount of advocacy for BFRBs in the last few years, and it was together that we decided to start a support group in London in 2016. She was also more open with others about her experiences with trichotillomania and had

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<sup>8</sup> BFRB Awareness Week (previously Trichotillomania Awareness Week) runs from the 1<sup>st</sup>-7<sup>th</sup> October each year, and was started by the TLC Foundation for BFRBs. It is an important time for people in the community to come together.

been spreading the word at the school that week about her fundraising. In the playground that day she had come across a mother who had said that trichotillomania was not a “big deal”, and “at least she wasn’t a drug addict”. Dhaya was very upset and angry at this statement, and said she was “fed up” with people who just don’t “get how hard it is”. She said, “Yes, I may not be downing a bottle of vodka, but I feel like I’m doing this – [she lifted up the sleeve of her jumper and pretended to jab a needle into the vein in her forearm] I *feel* like I’m a drug addict. I *feel* like I need to go to rehab”.

Annie also referred to her hair pulling as an addiction: “It’s like a guilty pleasure, and then after I’ve done it, I feel dirty almost... I mean I enjoy doing it at the end of the day. And I think it’s kind of like, I’d never really call it an addiction to anybody that didn’t know about it but it is like an addiction, it’s like the more you do it, the more you want to do it as well”. Other people frequently described the strength of urges in terms of addiction, discounting the idea that hair pulling and skin picking were simply “habits”. Instead they described the building urges that increased in strength until they were satisfied, often requiring people to stop what they were doing and go to the bathroom and pick or pull because until they did they would be unable to think of anything else. At a group meet-up in London one month in October 2016, Lewis told us about a time when he was at work and he felt his urges building. He said it felt as though there was something itching, under his skin that he had to get out. He had been sitting at his desk trying to work but the sensation in his face, and under his skin was all that he could focus on. He went to the bathroom and picked for some time, until his cheek was bleeding badly, and he had created a small hole in his skin. Too embarrassed and ashamed to return to his desk, he left the office for the day and later emailed an excuse about there being an emergency at home. He said that facing his colleagues the next morning with a large scab on his face was “humiliating”.

Much of what has been expressed in these examples relates to the idea of control and agency. Anthropology has historically treated the body as an object that can be acted

upon, manipulated, altered and transformed (McDonald 2018). But the turn towards embodiment theories have acknowledged the body as an “experiencing agent” (Csordas 1994: 2). In the descriptions above, we see how the body itself is felt to have an agency of its own, moving habitually by its own accord, controlling thoughts that become preoccupied with its sensory needs. My interlocutors often spoke about the body and the mind as separate, in line with the self/body duality of the Cartesian divide. Although many anthropologists have critiqued this way of understanding the body (Lock & Farquhar 2007, Scheper-Hughes & Lock 1987), others have argued that local understandings of mind and body as separate remain present and valuable (Ecks 2009). These distinctions are useful in expanding our conceptualisation of embodied experiences, and show how the BFRBs the body is both connected and disconnected to the mind and the self.

Hay (2010) has highlighted the way that lack of agency increases suffering among people who have invisible chronic illnesses, especially in industrialised societies where productivity is emphasised. He argues that the focus on productivity is linked to self-worth, which is measured by work and busyness. As a result, when people are not able to achieve high levels of productivity, it negatively impacts notions of the self. In particular, he notes that people feel guilty “wasting time” (Hay 2010: 3). If agency is in fact “fundamental to our human experience” (2010: 260), as Hay suggests, then for my interlocutors, the felt lack of control over their bodies may arguably increase the level of suffering caused by BFRBs. This certainly represents people’s concerns over “wasting time”, the guilt that people experience after being in the “zone” was more often connected to the visible damage that had been caused during that time, as well as the time itself being “wasted”. Agency certainly plays a part then, as the mind and body act in conflicting ways to create physical and emotional damage,<sup>9</sup> both of which make the person feel out of control.

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<sup>9</sup> Chapter Two will feature a more thorough discussion on the role of emotions and affect.

In these descriptions, we can see the multi-layered aspects of BFRB embodiment, with a combination of sensory rituals, trance-like states of being in the zone and strong urges that feel like addictive tendencies. Annie also mentions what is arguably one of the most important elements of embodying BFRBs: guilty pleasure.

### **Friend and Enemy, Pleasure and Disgust**

While in the “zone”, it was often mentioned that pulling and picking can create a sense of “calm”, and yet these moments are usually followed by feelings of guilt and disgust. These sensations are important in people’s relationships to their behaviour, and largely influenced their ability to stop, making it difficult to imagine life without their BFRB. Here we see how long-term pulling or picking becomes an important aspect of the self with deep-rooted, embodied meaning.

Given the shame and embarrassment associated with BFRBs, and the ways that they can impact quality of life, limiting social interactions and affecting relationships, the question I often asked in interviews - “do you want to stop?” might seem easily answered. But instead, replies to this question usually came with hesitation. Undoubtedly hair pulling and skin picking offered something to people that was difficult to let go of. This dilemma was described by Milcho, the keynote speaker at the TLC conference in April 2018: “I decided I had to shave my head to get rid of this urge, and I had planned to do it on that Friday... in the week running up to it I felt like I was in mourning. I knew I was about to pull someone I loved out of life support. Someone was about to die and I was filled with so much sadness.”

Milcho was not the only person who personified their BFRB in these terms, and I heard similar statements in interviews, in support groups and in online discussion forums: “[Hair pulling] is my best friend and my worst enemy”; “It’s a complete love hate relationship [with my trichotillomania]”; “It’s just part of me, [losing it] would be like losing my left arm”; “I can’t imagine life without [my BFRB]”. One of the reasons that

people feel so connected to their BFRB is the time that they have been engaging in this behaviour. Engaging in a repetitive behaviour for such a significant length of time engrains it deeply in the body, and this is reflected in the compulsive nature of BFRBs that appear like “hands have a life of their own”. Again we can see how temporality shapes experiences of BFRBs and how repetition becomes routine, making home in the body and thus becoming part of the self. Moreover, this long-term habit-forming experience is especially hard to break due to the multiple sensory rewards that hair pulling and skin picking offer people, including tension relief, satisfaction and pleasure.

The pleasure gained from these behaviours sits alongside the risk of stigma and emotional distress that they can bring. In a Facebook support group someone asked the question: how would you describe trichotillomania? To which someone answered: “It feels wonderful. Almost like a drug”. Another wrote: “A self-pleasuring act of self-destruction”. During my conversation with Nicole in Edinburgh, she said:

It's like my third arm! [Laughs] And that's the thing, sometimes you don't *need* to do it, but you just do it because it's *lovely*! [Laughs] It's so bizarre, it's kind of a love hate relationship, because you love to do it but you hate yourself after, because you've just disappointed yourself because you were like 'I wanted to keep that row of eyelashes and I just enjoyed pulling them out!' [Laughs, Nicole's emphasis].

Michael had a slightly different experience of his BFRB, finding it difficult to classify himself as either a “skin picker” or a “hair puller”. When I met him for coffee in London's Kings Cross station, he told me he thinks he suffers from trichotillomania, although he feels that his condition does not neatly fit the criteria for either hair pulling or skin picking, as he has the urge to bite the hair from his arms. He had recently found the name “body-focused repetitive behaviour” and excitedly joined a Facebook support group, where he found details about my research. When we arranged to meet by email, he told me was looking forward to meeting his first “BFRB friend”. Despite having not shared his BFRB story fully with his fiancée, Michael surprised himself at how easy he found it to talk to me about his experience. During our chat he said:



“When everyone else says: ‘Why d’ya do it’? The answer I want to say, which I can’t say is: Because I enjoy it! It makes me feel happy.”

Other studies on addiction can help to make sense of these experiences of BFRBs, and show that these sentiments are common in narratives of people with addictive behaviours. They show that addictions can be considered a “persona” that transforms the illness experience into a person, who has control over peoples’ bodies, showing how the addictive behaviour is both part of the self and not part of the self, embodied and disembodied (Brodie & Redfield 2002: 14-15). But while some addictions rely on “access to the stimulant” (Ulrich 2015: 98), BFRBs are comparable to other conditions where the body is at the centre, like self-injury and eating disorders. Warin’s (2010) ethnographic account of people living with the diagnosis of anorexia shows how people often express combined feelings of pleasure and disgust towards their actions and their bodies. Warin’s informants frequently described their relationship with anorexia as both “friend and enemy”, or as an “abusive lover” (Warin 2010: 97). Chandler (2013) has also noted the nuanced ways that pain is experienced for people who practice self-injury, who sometimes express feelings of pleasure. This contradiction of mental disorders has also been highlighted by Lavis, who argues that the seemingly “harmful” act of purging food for people with eating disorders can instead be conceptualised in terms of “care” (Lavis 2015). The dualities of care and harm, pleasure and disgust, friend and enemy, epitomise the conflicts that exist for people living with hair pulling and skin picking behaviours. On the one hand they body appears to be acting out of control, with urges stemming from “inside” and creating damage on the “outside”, but at the same time the “zone” and the “pleasure” that comes from satisfying urges acts as a comfort. So while the BFRB body is concealed, and the visible effects are resented, the familiarity of BFRBs as a comfort creates a complicated relationship between the mind, the body and the self, making it incredibly hard to let go.

## Time for Acceptance

Having gone through the deeper embodiment of BFRBs to show how the self, the mind and body are interconnected, often in conflict, I will now return to the idea of the life course to show how time can alter the way the BFRB body is perceived.

Catherine had become accustomed to wearing her hair in a high bun for the majority of her life, and said that even those closest to her thought it was just her “signature style”. Her hair pulling area was commonly the crown of the head, and so she had become used to using the surrounding hair to cover the bald spot in the centre of the top of her head. This sort of hair styling, had become skilful and practiced after years of having to cover the same spot. Catherine admitted that she wished she could wear her hair in other styles, but felt at least it was in keeping with her image as an older woman, and therefore easily hidden. But this type of style was influenced by time, and in a separate interview with Catherine’s husband, Hamish, he gave his own perspective on her changing hair styles:

She’s always kind of worn her hair up, and that’s part of, I suppose you’d have patches that were visible if you didn’t wear it in a bun. And I think that now we’re in our fifties that looks alright, I suppose that would’ve looked more unusual in your twenties... and, you know, Catherine’s sometimes commented that people tend to think she’s a bit more mumsy than she is, and I think that may be partly to do with the hair and the way that she wears it.

I got a similar impression from Catherine during our interview, when she told me about when her daughter shaved her head. She admitted she would love to do the same as she thought it would help solve her hair pulling. Unlike other women who were afraid of “looking gay”, Catherine wasn’t necessarily concerned about how a shorter hair cut might raise questions surrounding her sexuality. Instead, she said, “When you get to a certain age... a shaved head just makes people think you’re sick”. As we have seen across this chapter, gender, race and the life course affect the way BFRB bodies may be perceived by outsiders when revealed; and the potential for stigma connected to

female hair loss became an increasing concern for Catherine at this stage of her life. While Catherine talked at length about the daily aspects of trichotillomania that bothered her, ultimately she said she had learned to accept it over time, “I’m fifty-four, and I think you kind of get to that stage in mid-life where you kind of stop caring... you get over that arc and you’re like, d’you know what? It’s not like I’m an alcoholic. I’m not a recovering alcoholic. I’ll just always be: ‘Hi my name is Catherine, and I have trichotillomania’. It’s just part of my life.” Catherine accepts that she has a hair pulling disorder that she will probably never overcome. But she also acknowledges the way her hair pulling has left its mark on her body, and therefore she accepts the ongoing use of techniques of concealment.

Time has played a role in Catherine’s acceptance journey, as it did for many others. But there were also important social aspects that contributed to this, evident among the older people who attended TLC conferences. In April 2018, I heard a woman speak as part of a workshop on recovery. She said,

There’s something about turning fifty, I would have thought I’d have this beat by now. I didn’t find TLC until a few years ago, and I realise that part of my recovery is dealing with the shame. I’ve spent forty years hiding, and that is a sign that I am terrible. I would like to think that in the next fifty years I can learn to feel lovable. I love the idea of acceptance, even if I’m on a rollercoaster with this until the day I die.

Here we see the way that perceptions of the BFRB body and the long-term feeling of needing to hide can deeply influence notions of the self. Techniques of concealment cover the BFRB body, but they also reveal the shame of living with BFRBs that people attempt to hide through covering their bodies. For this woman, attending a TLC conference marked the moment when she felt able to confront this perception of self, and to question her life of hiding.

## Conclusion

In this chapter I have introduced the many techniques that different people use to conceal the effects of their repetitive behaviour on the body. Hair loss and marks from skin picking are covered with make-up, hair products and accessories, and creative hair styling. But life with hair pulling and skin picking is also kept hidden, as people avoid social situations that may risk it being revealed, as well as keeping their behaviour secret from loved ones. These efforts are time-consuming, arduous and frustrating, and they highlight one of the major difficulties of living with a BFRB body which is considered embarrassing and shameful. However, these techniques of concealment also reveal certain social norms for men and women. We see through the different methods of covering the visible damage of a BFRB that gender, sexuality and race influences the options available to people in their choices of different techniques of concealment.

For many of my interlocutors with trichotillomania, certain hair styles were used as a method of keeping hair loss hidden. Techniques of concealment are gendered, and reveal normative beauty practices for men and women, deemed acceptable for covering up BFRB bodies. As these experiences show, hair is meaningful for women in various life course milestones, and their experiences with trichotillomania remind them of their lifelong struggle with the disorder. These milestones also highlight the taken-for-granted moments in life when people feel they can be themselves, and enjoy normal, special events like ordinary people. These moments, and the many moments in everyday life where people feel the need to hide their BFRB, creates further isolation and hiding. Evident in this chapter is the way that perceptions of the self are connected to one's relationship to the body. I have argued that by looking closely at the way people use techniques of concealment to cover the BFRB body, we can reveal the complexities of BFRB experiences as well as the wider sociocultural factors that influence stigma.

Certain aspects of BFRBs reveal the confusing relationship people have with them. They are repetitive; they are both part of the self, the mind and the body; people feel like they are addicted to the body itself; they make people feel calm (trance) and happy (pleasure) and thus hard to let go of; they make people feel disgusted and confused about their identities, while also making people feel comfortable and safe in themselves.

I have shown how temporality influences techniques of concealment, and experiences of BFRBs throughout the life course. The necessity to routinely cover hair loss and scars in methodical ways every day creates an embodied expertise to these techniques, where people rely on skilful methods of hiding, like “masters of disguise”. Time not only influences acceptance, and as this thesis progresses I will show how connecting with other people who share experiences of the BFRB body can lead to a notion of acceptance, and create a kind of self-care and self-compassion for the BFRB body.

The desire to keep BFRBs hidden was sometimes due to the fear of what family members might say. But it was also influenced by negative responses in the past that had caused people to go further into hiding and cover up the fact that they continued to pull hair or pick skin in private spaces. Some people managed to hide their hair loss or scars so systematically that family members were unaware for many years. In the next chapter, I will show how my informants attempted to discuss their hair pulling with parents, and uncover moments when hair pulling brought unwanted attention from families. These negative memories were recounted to me often with a great deal of sadness but they also revealed the ways that parents shared intersubjective experiences with their children, leading to blurred boundaries between care and harm.

## Chapter 2

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### Kinship Relations: Care, Harm and Intersubjectivity

Solina and I met each other at the TLC conference in 2016 which was held in Dallas, Texas. She was attending as a student from Glasgow University, where she was completing her undergraduate psychology dissertation on skin picking disorder. She had put together a research poster with her lecturer and my friend, Jude. Solina was shy, and hid behind Jude's bubbly and chatty personality, which was even more excitable in the conference environment. Over that weekend in Dallas, I was able to speak to Solina alone, and I found myself asking her the question that I once dreaded myself: Why did you choose to study this disorder? Her eyes began to fill with tears as she quietly admitted that she had "it". I reached out and hugged her, and said it was a very brave thing to admit. We talked longer and I told her about my own journey. Finally, she asked me not to share this information with anyone; saying that apart from Jude, I was the only other person who knew about her skin picking.

Two years later, Solina returned to the 2018 TLC conference in San Francisco to run her own workshop on the topic of "coming out with BFRBs". It was a small group, around ten people from about age eighteen to sixty. Apart from one father, the rest of the group were women who had a BFRB. Solina began by explaining why she had decided to run this workshop, and how this topic represented the moment she was at in her own journey with skin picking, having begun to open up to some people over the last few years. She explained that the session was not going to direct anyone towards "coming out", but instead she hoped we might share experiences about coming out, or discuss our worries surrounding this moment. She told us a bit about her own story, and explained that coming out for her didn't mean telling everyone all of the time, but instead was a slow and gradual process, and only a few people close to her knew her secret.

In Chapter One, I described how make-up can be understood as a technique of concealment and although it helped Solina to keep her BFRB hidden from family, it still raised questions about *why* she was wearing so much foundation on her face. Solina explained that following the TLC conference in 2016, she was eventually able to tell her parents about her skin picking and why she felt the need to wear make-up. She described this moment as a relief, as she was then able to explain the time this took, and they could help her to avoid stressful situations when she was caught off-guard. She gave the example of when a family friend might come over in the evening, when she would usually be in her room without make-up. Now that her parents knew that she preferred to wear make-up to cover her skin, they would give her a prior warning so she had time to apply the foundation before any guests arrived. Solina was now able to spend time make-up free with her parents, and they were able to support her in her ongoing process of concealing her BFRB from other people in her life. Everyday examples of this kind were one of the practical benefits for her about sharing her BFRB experience with her family and demonstrates how techniques of concealment are relational. For Solina, revealing the BFRB body positively influenced care practices from parents, however, this was not the case for all of my interlocutors and often family members brought increased stigma to experiences of BFRBs.

In this chapter I consider the shame of living with a BFRB body described in Chapter One, and describe how people negotiate revealing BFRB experiences to close family members. Building on the idea of kinship as a mutuality of being (Sahlins 2011), I show how the intersubjective experiences of BFRBs both connects and separates kin. I unpack the emotions involved in these experiences; anger, sadness and guilt as well as the mutual experience of loss. I demonstrate the tensions that these emotions bring up in family life, where silence, ambivalence and punishment become ways of coping with BFRB children, which, although harmful, can be perceived as forms of care. I show that the mutuality of being present in BFRB families has limits, and it is in these limits that we can see a conflict in families, with children struggling to communicate what they feel; parents struggling to understand; and both feeling uniquely implicated in

their own bodies and emotions. Examining the intergenerational aspects of families, I show how care practices are reproduced, and how the embodied risk of BFRBs creates a fear of passing on these disorders to children. Finally, I argue that the expectations of care present within kinship relations (particularly the care of a mother), become framed as ideal forms of care, which people attempt to reproduce in their self-care practices.

### Mixed Emotions for Parents

In April 2016, outside the Marriott Addison Hotel, Dallas, I sat in the warm Texan sunshine by the pool with Mandy and Dale. I had asked them to talk to me about their experiences of caring for children with trichotillomania. At the time, Mandy's daughter, Frankie, was eleven-years-old and had been pulling out her hair for two or three years. Dale was a hair stylist who came to the TLC Foundation's annual conference to do haircuts for kids. He was also good friend of Mandy's, and sometimes visited their house in New York City to cut Frankie's hair in the privacy of their home. Mandy began by telling me about how Frankie's hair style changed over the years, and that when they decided they needed to shave Frankie's head, Mandy made the decision to also shave her head to support her daughter. The conversation quickly shifted to the relationship between mothers and the visibility of hair pulling daughters: "I don't think it's as shocking to see a boy with his head shaved, you know, society, when they see a girl with her head shaved, or even buzzed, you know it's a whole gender thing." Mandy then went on to say that the free wig they received from the Hair Club<sup>10</sup> helped Frankie to feel more comfortable at school. I asked Dale if he thinks these methods help. He responded promptly:

No. They're not there to help people, I guess they're there to help people *cope*... But I'm noticing a lot of it is with the mothers, as a hairdresser when I take the mothers aside - not you [he touches Mandy's arm] a lot of

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<sup>10</sup> Hair Club is an American company that provides wigs and hair products to people with hair loss. They offer free wigs to children under the age of 18, and they sponsor the TLC conference each year.



them, it's like they're mourning the loss of their daughters' femininity, a lot of women are just like, 'I miss their long hair' [Dale's emphasis].

To this, Mandy nodded her head and interjected:

When you look back at pictures of them [your children], when they were young and they have full heads of hair... I don't think it's the hair that we mourn, but the lack of *awareness*, that we were so blissfully unaware that anything like this could potentially happen to us... because you don't see it coming, and it's something that's relatively obscure. It was very sudden. Like wildfire [Mandy's emphasis].

Mandy insisted that it is not the hair that she mourns, but in her later descriptions it became clear that the visible loss of hair had become a mark of losing something else in her daughter. Mandy recounted the way that she would routinely brush Frankie's hair before bed, but when the disorder began, she would sob each night as she did this. During the conversation she admitted that now she realises how this reaction might have made Frankie feel increased shame and guilt, but she said at that time she was still "grieving".

The sudden onset of trichotillomania, and the fast pace in which visible change occurs, creates fear and worry for parents. But these experiences also extend beyond the visual dimensions of loss, and translate into grief and guilt. Camila, the mother of fifteen year-old Megan, whom I interviewed in Washington, DC, described her experience in similar terms:

Obviously it was a very new issue for us, no one in our family had had that issue so I wasn't aware of it, I didn't know *anything* about it and obviously as a parent you start to second-guess yourself you know 'what did we do *wrong?*' You know, if you're not experienced with it then you're just floating through and trying to figure out how to deal with it... But she's learned to deal with it in the social aspect, because obviously as a mother, you know I want her to be healthy not only physically but mentally, but I worry about the mental aspect, the physical aspect of it and obviously she's in these critical years as a *girl*, it's tremendously hard [Camila's emphasis].

Like Mandy and the mothers described by Dale, Camila mentioned her concern for her daughter in connection to her identity as a girl, and for mothers of daughters, this identity is undoubtedly linked to ideas of femininity reflected in their own identities as women. They express shared emotions with their children, loss, sadness and confusion - but at the same time these parents are unable to understand what their children were going through. They were both connected and disconnected to their children though their bodies.

Kinship relations are in many ways intersubjective, as Sahlins (2011) and Stasch (2009) have noted. By considering kinship as a “mutuality of being” in which parents and children can share affective and bodily experiences of both joy and sadness, Sahlins shows that “experience is more than the individual” (Sahlins 2011: 3). For Sahlins, kinship is built on these experiences of mutuality, in which families are implicated in one another through “bodies, feelings and experiences”, and he gives examples of the common scenarios in which this mutuality of being is produced and felt, including sharing food, shared memories and in shared suffering (Sahlins 2011: 5-11). Stasch (2009) called this aspect of kinship “intersubjective belonging”, and in his ethnography on the Korowai of West Papua, he claims, “kinship is belonging” (2009: 141, emphasis in original). Stasch argues that for Korowari the bonds between parent and child are the “extreme of what intersubjective belonging can be”, and “are probably the most emotionally intense social bonds of Korowai life” (2009: 141). But Stasch does not go on to unpack these emotions. For Sahlins, although there is an implied focus on the physical body, the “being-ness” of mutuality of being, is less focused on physicality and more on symbolic feeling (2011: 227). But neither Stasch nor Sahlins demonstrate the ways that bodies and emotions are linked.

In the examples I have given of families dealing with BFRBs, we can clearly see that mothers are bounded to their daughters through both physical bodies and emotions. For Mandy and Camila, their sadness and grief at seeing their child’s hair diminish is connected to their shared bodily experiences with their daughters, and their shock at

seeing their child's physical appearance change. As Mandy watched Frankie's hair diminish, she also experienced a sense of loss, a sensation of what her daughter is feeling and representative of a loss in their intimate bond as mother and daughter, seen through the change in Frankie's physical body through her appearance. Building on Sahlins' work, I argue that not only are parents of BFRB children tied intersubjectively to their children through emotions and physical bodies, but that through these emotions and physical bodies it becomes clear that mutuality of being is gendered.

Mandy told me about the parent-only Facebook group she administrates. She said: "It's just a place for parents to go and vent and cry and rage or share stories of success or methods, or medication questions, product questions, Hair Club for kids questions... so it's a nice place for everyone to convene in a safe environment where they're not feeling judged". I asked her: "And what would you say is the most common thing that comes up in that group?" She hesitated for a moment and then replied: "Sadness. That our kids are afflicted with this, and we don't know how to help them, and often times they don't know how to help themselves, and sometimes they don't wanna help themselves, sometimes they are adamant and defiant about receiving help and you realise that it's their journey to be on, it's not ours." According to Mandy, one of the most frequently mentioned concerns in the Facebook group is connected to fathers: "One of the biggest issues that comes up is the dads, dads just don't understand it." I asked her how many fathers are in the group, and she said a "tiny" amount in comparison to the mothers. I asked her why she thinks that is. She responded: "The majority of our members, their children are girls, so it's the mother who's grieving the most over what's happening." I asked Mandy again about the Facebook group and what discussions come up between mothers' about fathers' ways of coping with trich:

The dads tend to be more angry about it, and the moms tend to be more sad about it. You know, there's anger in the mom groups too, but it's fleeting, where the dads take it very personally. You know I think more so the dads have a vision of what their daughters are going to look like, and while women in general have a better understanding about changing

appearance and being chameleons in our own skin and being able to dye our hair and cut our hair and change our style, men have a harder time.

When I asked Mandy how Frankie's father deals with her hair pulling, she said: "He's just not an active force in any of this, you know the therapy, the... but anytime I say you know: 'we need \$2,000 dollars so that I can fly with Frankie to Colorado and go to a trichotillomania retreat', he's the first one to get online and book our flights for us. And that's his way of supporting us". I asked Mandy if her husband had ever attended a conference, and she said: "No, he couldn't do this [...] He can't. It's a very vulnerable place to put yourself and he's just not that... yeah." While Mandy complicates the notion that all mothers miss their daughters' long hair, she reminds us that fathers also struggle with the visible changes in their daughters. We might assume that this is because mothers and daughters share bodily attributes of gender, connecting to "emotional" intersubjectivity. However, this notion is conflicted by Mandy's later statement that fathers sometimes miss their daughters' hair more than mothers. Here we see how families are connected intersubjectively in complex ways, which creates different emotions for both mothers and fathers. Further, Mandy mentions that fathers care in material ways, supporting their families from a distance and making it possible for them to attend a conference, but seemingly unable to engage in the emotional process that the conference involves, and so gendered emotions are linked to gendered care practices. However, the idea that men are "unable to engage" with the emotional experience of the conference, was not the case for all fathers. In a conversation with Mark Maxwell who attended with his wife, Penny, and daughter, Tiffany, in 2016, he said:

I've learned some things, I think what I struggled with at first with the disorder initially, y'know as a father right, you just wanna fix everything, so for me to look at her and say, 'Hey Tiff stop doin' that,' that should be enough. But that's not the way it works. And it took me a little while to learn that. And I think once I learned that I personally went through a pretty significant stage of guilt, y'know for my own career growth I've moved the family around over the last six years, and those coincided with the disorder starting and then getting progressively worse, so for me it was the associating of 'this leads to that' - I did this to my daughter. So those

are just things that I had to work through, and now I think I'm in a pretty good place, I don't look at her anymore and just see the bald spot, or see the wig, or see the no eyebrows or no eyelashes, I get to look at Tiffany now and just see all of the wonderful things that are her.

These examples reveal the ways that parents and children share a mutuality of being, with intersubjective emotional experiences. Mark's experience highlights the way that fathers as material carers experience guilt as a result of economic choices which they fear negatively impact their children. Unpacking these experiences of affect, it is clear how emotions go beyond individual experiences, as much of psychology assumes (Lutz & White 1986), instead showing that affect is deeply relational and therefore "can only be understood as a relational dynamic between actors and the complex socio-material environments in which they are embedded" (Röttger-Rössler & Slaby 2018: xiii).

Although many people described fathers and mothers as separate in terms of emotion and care practices, in my conversations with parents, sadness and anger were not always split along gendered lines. The sadness and rage that Mandy observed in the Facebook group also came out in an interview with Camila, who admitted that she has struggled between being supportive, and getting frustrated and angry:

...[f]or the longest time I was taking ownership of it and just trying to make it my problem and that was really hard, I mean just the stress and the frustration because you want to talk to them about it but they don't want to talk about it and you wanna help them and you wanna make them stop, so it's like you go between being soft and gentle and 'what can I do for you?' to being angry because you're like 'why can't you stop?' It's such a struggle, because you're feeling helpless because you can't help your child and that's *really* difficult [Camila's emphasis].

For Camila, like many other parents, anger and frustration came out through a sense of powerlessness, because you "can't help your child". I argue that this powerlessness is where we see the limits of intersubjectivity; parents might *feel* loss with their children, but they lack the control to *stop* it. In my examples above, we can see that mutuality of being is entangled with confusion, risk, guilt, and failure. By examining

these aspects of kinship, I argue that families are inherently tied up in both love and harm, which challenges our assumptions of care practices in the family.

### **Boundaries Between Care and Harm**

Sahlins' insight on kinship as a mutuality of being triggered deeper discussion from anthropologists who praised, critiqued and expanded the term. Of these critiques, Carsten (2013) has argued that Sahlins reinforces the positive aspects of kinship that many scholars have focused on. She says, "'Mutuality of being', on the whole, emanates a warm, fuzzy glow rather than a cold shiver" (Carsten 2013: 246). For Carsten, kinship is full of negative qualities. These are aspects of kinship that Stasch also brought to our attention, and he argues that intersubjective belonging often involves risk and confrontation. In the context of the Korowai, although the parent-child relationship epitomises intersubjective belonging, it also highlights the risks of intersubjectivity, as newborns bring miasmatic danger through the process of childbirth (Stasch 2009: 150). Several others have noted that kinship has a dark side, involving risk, violence and abuse (Geschiere 2003), as well as conflict and crisis being inherent to kinship (Reece 2015). According to Reece, "conflict and crisis are not simply unfortunate things that happen to families and are best avoided; they are continuously *produced* by kinship, and *produce* kinship in turn" (2015: 37, emphasis in original). Reece is one of the few anthropologists to expand the dark side of kinship to include "negative" aspects of care. She says, "care – like almost every other defining expectation, responsibility, or experience of kinship –produced conflict and crisis; and more than that, it was negotiated through conflict, accessed and even achieved in conflict" (Reece 2015: 40). I build on these notions of kinship to argue that care, too, can have negative qualities, and that these "bad care practices" are influenced by kinship's inherent intersubjectivity. In the examples that follow, I show how some of the reactions from parents towards their hair pulling children can be understood through a shared emotional pain that they experience with their children, resulting in blurred boundaries between care and harm.

The topic of “pain” was contested among my interlocutors with BFRBs, and as I mentioned in Chapter One, people rarely described physical pain from pulling or picking behaviours. Pain was described in negative terms, rarely present during the time when pulling or picking, but sometimes following it, when people felt a “rawness” in areas where a great deal of hair had been pulled, or skin had been picked. In the case of self-injury, Chandler (2016) has demonstrated the unique relationship between physical pain and emotional pain, as they work together to release tension from inside the body to outside. The idea that the outside body and the inside body can work together, reconfirms the idea that pain can be productive and communicative (Das 1996). For people with BFRBs, the feelings of pulling and picking, although rarely painful, were also productive, releasing tension, and creating a sense of satisfaction, although this was almost always followed by feelings of guilt, disgust and sadness. While physical pain was not present, emotional pain could be used to describe the negative emotions that accompanied BFRBs. In the examples of parents above, I argue that parents and children with BFRBs both experience a level of emotional pain in their shared mutuality of hair pulling and skin picking. But the absence of physical pain was difficult to communicate to family members, and instead parents assumed that hair pulling and skin picking were causing physical pain, which was reinforced to them through the physical damage on the body.

As I mentioned in Chapter One, the visible effects caused by a BFRB are an important factor in experiences of shame, alongside complex and confusing embodied urges. But while people feared public reactions to hair pulling and worried about social stigma, ridicule from strangers rarely occurred. Instead, the stigmatisation of living with hair pulling and skin picking was often reinforced at home, and frequently connected to one’s physical appearance. Loved ones were frequently described as being “unsupportive” and “unhelpful”, with parents often saying too little, or saying too much. There were some common responses that my informants received from parents including “why can’t you *just stop?*”, and people frequently said about their family members: “they just don’t *get it*”. In support group settings, one of the most

frequent conversations that came up was the issue of communicating BFRB experiences to family members, and how to explain why it was difficult to stop, or how satisfying or enjoyable pulling and picking was. It appeared that family members often misunderstood their behaviours as “self-harmful” or “self-destructive”, and people living with BFRBs found it difficult to admit that they felt pleasure rather than pain.

In conversations with parents, I regularly heard the language of harm and pain: “You see your child hurting themselves”; “You see your child in pain”. These statements were often followed by an intention to do something to change this: “You want to fix your kid”; “You want to take away their suffering”, alongside the discovery of their lack of control over the situation, “But you can’t do anything for them”; “You feel so powerless”. The concept of intersubjectivity allows us to consider the ways that parents and children are linked in experiences of pain, albeit in very different ways. As we see from the detailed examples above, the visible hair loss of daughters Frankie, Tiffany and Megan can lead to the assumption that pulling out hair is painful, and therefore cause parents Mandy, Mark and Camila to perceive hair pulling as a form of self-harm. They worried about their children’s social lives, and prospects of bullying as young women who had altered body images from the social norm for white American teenage girls. So at the same time as their daughters were experiencing emotional harm (and perceived physical harm) so too did the parents experience emotional pain and suffering as they watch their children suffer, and they are unable to help.

When I met Michael, he asked me if I thought BFRBs were a form of self-harm. I said I wasn’t entirely sure, and asked him what he thought. He responded:

Sometimes it’s completely self-conscious, but I can be quite negative, most of my anger and frustration is towards me, I’m not angry to anyone else, I’m patient, I care about anyone, so it’s all inwards. And I think when I’m frustrated and angry I do it. And I’m not sure if it’s a pain thing, like I want to inflict pain on myself, cause I have heard people say - like my mum said it’s like self-harm, and I said: ‘Well is it?’ ‘Cause I don’t wanna hurt myself. Like I don’t know. I don’t think it is self-harm, I wouldn’t slit my wrists... it relieves tension.



Michael and his mother go by the assumption that self-harm is about pain,<sup>11</sup> and for this reason Michael discounted the label. He said he does not intend to “hurt” himself by biting his arms and pulling out the arm hair. These actions in fact do not cause him any pain, but instead relieve tension; as he put it, “What I wish I could tell them is it makes me happy”. The disconnection Michael raises here between his mother’s understanding of his BFRB and his own, again highlights the reality for parents that, although they share a mutuality of being with their children - they cannot control their experiences of having a BFRB. Parents feel emotional pain caused by the belief that their children are causing themselves physical pain. However, as I mentioned in Chapter One, these misconceptions surrounding pain and BFRBs are also present in experiences of self-injury and eating disorders (see Chandler 2016, Lavis 2015 and Warin 2010), and in Chapter Four I will show how people with BFRBs seek to change these narratives.

While dichotomies of mind and body have been criticised as reinforcing separations between physical and emotion experiences (Crossley 2001), we can see that families understand pain in a variety of ways, that are often interlinked and cannot easily be understood through dualities of body and mind, or physical and emotional, although they are often described as such. Ultimately, pain is a negative experience that families wish to overcome for their loved ones, and that people with BFRBs attempt to resist by explaining the pleasure, but struggle to communicate this sensation to others. Here we see that despite pain being experienced intersubjectively, the differences between physical and emotional pain highlight the powerlessness and frustration that parents feel over their BFRB children, and this can lead to harmful forms of care.

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<sup>11</sup> Chapter Four will discuss this issue in more depth, explaining the push-back from the BFRB community to the self-harm label.

## Tough Love

Heather and I had agreed to meet for the first time in Costa Coffee near Marylebone station in London. It was a dull November evening around five o'clock, and she entered wearing a dark blue wool coat that reached her ankles, her face looking flushed from the cold. She is a short woman with shoulder-length brown hair that was tied back into a low pony-tail. Heather was born in Wales, and talks in a soft English accent with an intermittent twang of Welshness. At first, she appeared uncertain and nervous, but we ordered tea and she soon warmed up and became very chatty. We sat together for over an hour, and the conversation quickly became quite personal as she opened up to me about her experiences with her father. When I asked Heather how her family had dealt with her trichotillomania, she told me about the time she had discovered "it had a name", and how she tried to use this discovery as a way to break the silence surrounding her issue with her parents. Heather's father was a medical doctor, so she thought he would be understanding and supportive. At this point in her life, she was in her twenties and had just read a magazine article about trichotillomania and realised that there was a medical name for her hair pulling. She picked up the phone to tell her father about what she had found, and she was excited about the prospect of getting help:

The first thing I did was ring my dad, and up 'til that point we hadn't ever addressed my trich, never spoken about it even though there was one period in primary school where all of this was gone [she circles the crown of her head]. And I said to my dad - and I was feeling really brave - I said, 'You know I do this thing?' And he said, 'Yes,' and I said, 'Well, it's got a name, can you do some research for me, can you ask some people?' I phoned back a few days later to ask if he had done some research, and he said, 'No, no, no, no, your mum says not to indulge you.' [She began to get tearful and her voice wobbled]. So I don't talk about it with them. And I don't [now] and I don't think I will [again]. There's no point.

As Heather recounted this conversation to me, her eyes filled with tears and she finally said she would prefer to talk about something else. Her memories of this time were clearly difficult to recall, and it wasn't until I had visited Heather in her home on several

occasions during my trips to London, that she chose to open up more about her relationship with her parents. She talked about her mother, who appeared to withhold affection from her even at times when Heather had longed for her support. She described an evening when her father had tried to console her with a hug as she was “sobbing uncontrollably on the couch” and her mother had told him not to “indulge her”.

Heather described the silence and lack of affection from her parents quite explicitly, but I also observed similar struggles when I met her partner for the first time. It was January 2016, and Heather and I had attended the first ever London support group meeting, which I had helped to establish. We were both excitedly talking about the day when Rory<sup>12</sup> joined us for dinner at Pizza Express near Leicester Square. For some time, we all sat and made small-talk, and I was surprised by the obvious silence from Rory about the day. I knew how important this support group session was for the people who attended, as it was the first time some of them had met other sufferers, and I was surprised that Rory had not yet asked us how the day had gone. Rory left to go to the bathroom, and as soon as he was out of earshot, Heather leaned in closer to me and said: “Rory’s not one to ask questions, he doesn’t want to seem like he’s prying – but he’s there if I need to talk, his door is always open”. She implied that this was his approach to all issues, and I said “that must be difficult to deal with in a partner”. Heather frowned, perhaps not understanding what I meant. We didn’t have time to follow it up at the meal, but I couldn’t help feeling a great distance between them later that evening when Heather and I chatted in their living room, and Rory sat in the corner of the room at his computer with his headphones on. In my fieldnotes that evening I wrote:

*To me it seems very sad that she has to approach emotional or sensitive topics all the time without someone she loves showing an interest first. How does she feel reassured that he cares? Does that not make it more difficult for her to open up? How do we know people care if they don’t ask us if we’re*

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<sup>12</sup> Rory was aware of Heather’s hair pulling, and also that she was taking part in my research.

*OK? And how do we care properly if we don't know what to say to people who need help?*

Other people described experiences of silence and ambivalence from loved ones. Like Olly, a Scottish man in his thirties, who I met for our first interview in Linlithgow, who had never talked to his parents about his hair pulling while growing up. He described a time when he had mentioned to his father that he was still pulling his hair out, and his father responded with a brusque refusal to engage: “What? What’re you doing that for? That’s *stupid*.”. His mother, present at this conversation, neither intervened nor offered any support. Like Heather and Rory, the reaction from Olly’s parents was mirrored in his relationship with his wife, of whom he said: “She tries to be helpful, but she doesn’t really understand. Sometimes she’ll say, ‘Why can’t you just get over it?’”

As I outlined in Chapter One, silence and secrecy are important aspects of living with hair pulling and skin picking, and become tools to reduce the stigma inflicted, or feared from family members and others. Remaining silent is, therefore, a way of reducing the risk of the imagined stigma of BFRBs. However, people’s memories of silent parents who appeared to ignore their child’s suffering reinforced negative feelings. The silence from loved ones is linked to inaction; family members do not know what to *do* and therefore, do not know what to *say*. In turn, silencing is perceived as a lack of care. These “silent memories” (Kidron 2009) act as a form of communication between parents and children, an expression of how hair pulling is viewed in the household and in everyday life. In many ways, the silence, ambivalence and ridicule described here could be considered “normal” aspects of domestic life (Chapman 2006, Smart 2011), and contribute to the idea that that kinship is not always harmonious despite a number of anthropologists who frame family relations as positive (Fortes 1969, Sahlins 2011, Schneider 1980).

The examples I have presented trouble this assumption, and build on increasing notions that care may not always be positive, and can involve elements of harm. In

particular, my discussion complicates the idea that the relationship between mother and child is often hailed as an unquestionable bond through which care is attributed to love and affection. But just because love is not obviously positive, does not mean that mothers do not *care*. According to Scheper-Hughes, “Love is always ambivalent and dangerous. Why should we think that it is any less so between a mother and her children?” (1993: 353). The mutuality of being evident in kin relations creates shared experiences of secrecy associated with BFRBs, with children attempting to hide the BFRB body and parents trying to ignore it. For my interlocutors with BFRBs, the silence and ambivalence from parents is translated as “not caring”. But for the parents I spoke to, their responses came from not knowing what to do, and therefore not knowing what to say. It also became clear that because parents knew their children were embarrassed, drawing attention to hair pulling seemed like the wrong thing to do. Remaining silent and ignoring the problem, becomes an attempt to care.

Sahlins has argued that witchcraft creates situations of “failed kinship” (2011: 237), suggesting again that kinship practices ought to be obviously positive. In response, Carsten says, “Thus it is the ‘intent to harm,’ he argues, that distinguishes the positive from the negative. But rather than making a sharp opposition, we might want to draw out the more subtle gradations in qualities and intent between kinship as positive, and witchcraft as negative, force” (Carsten 2013: 247). Like Carsten, I argue that “positive” and “negative” forms of care are neither clear, nor obvious. Kleinman (2012), by contrast, has claimed that “good care” in medicine is based on the moral expectation to “do good”. He says, “The terms ‘taking care’ and ‘caring’ imply cultivation of the person and the relationship through practices of attending, enacting, supporting, and collaborating. What is at stake is doing good, for others and for oneself” (Kleinman 2012: 1551). But what does “good” and “bad” care actually look like? And how is are they understood by families who struggle to care for their children? I argue that in parents’ experiences of caring for their BFRB children, a lack of awareness of BFRBs influences their lack of awareness of how to care. And so they find ways to cope with

their child's hair pulling which results in a blurring of the boundaries between care and harm.

### **The Embodied Risk of BFRB Parents**

As well as silence and ambivalence, people also told me about many occasions where family members had ridiculed them for their hair pulling. For example, one woman was told by her mother, "You look like a reptile" because of her missing eyelashes. Others were the focus of family jokes about "clogging up" the vacuum cleaner with hair, or made fun of in their attempts to cover up with make-up. In particular, the struggle between mothers and daughters was often raised during my interviews with British women, who remembered harsh responses from their mothers in the past. By examining these memories, I will show how the mutuality of being between parents and children is further shaped by temporality and how the fear and risk of intersubjectivity is reproduced when hair pulling daughters become hair pulling mothers.

When I first met Lou in London, she was wearing the auburn wig that she had purchased from Beverley. When I asked Lou early on about her relationship with her parents, she said she wasn't ready to discuss it, and her eyes became tearful. Several months later at a support group meeting in London, she described her anxiety surrounding an upcoming family event. She told the group how her mother always made her feel bad about her hair, and on this occasion she had called in advance to check that Lou was going to be wearing her wig. This conversation had added to her anxiety in advance of the family gathering, and reminded her how her mother felt about the way she looked.

Rose had a similar story about her mother when she met Dhaya and I in London one evening for dinner. She told us about a recent family holiday in Spain where her mother had been "getting on at her" about wearing the wig in public, and making cruel

comments about how she looked without it. In the end Rose decided to ignore her mother, and quite happily took her wig off so she could go swimming in the pool with her daughters. As she told us this, she laughed and emphasised how ridiculous it was to wear a wig in thirty-degree heat. Despite the laughter and Rose's care-free attitude about the situation, in the end, this conversation became an intimate discussion between Dhaya<sup>13</sup> and Rose describing the painful memories of their mothers over the years.

For Rose and Lou, there appeared to be a deep sense of embarrassment and shame in their mother's reactions to their baldness. The BFRB body is made visible here, and challenged by daughters who attempt to resist the pressure from their mothers. At the same time there is a willingness to please their mothers, and a reinforcement of the embarrassment they already feel about their hair loss. These examples of emotional and physical harm highlight the dangers that come with intersubjectivity within the family. I have also argued that parents and children are connected in embodied ways that mean their responses to hair loss are not quite so straightforward. Furthermore, the complexities in these relationships are often hidden beneath the frustrations and sadness of mothers who see their daughters with extensive hair loss, and we see how the visibility of trichotillomania continues to be important to mothers, as they make comments on their daughters' appearances and insensitively request that their hair loss be covered up. Parents' sadness and frustration with their children becomes translated into silence, ridicule or punishment. On the one hand, these "harmful" reactions to their children appear to be failed forms of care. I argue that they are in fact care practices that are influenced by the lack of control that is present in the limits of intersubjectivity. When parents are unable to control the bodies of their hair pulling children, they are unable to control their care practices, and so the lines between loving care and harmful care become blurred. In what comes next I will show how this parent-child relationship has created

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<sup>13</sup> I will return to Dhaya's story at the end of this chapter.

intersubjective experiences across generations that shape understandings of love and care.

In August 2015, Shirley and I arranged to meet at her home in Edinburgh where she lives with her twelve-year-old son, Thomas. We sat having tea in her living room and her new kitten wandered and rolled around the living room floor. I asked her if having pets helped to keep her hands busy and away from her hair. She laughed and said, "Yes I suppose, as long as I don't start pulling out her hair!" I laughed and then said that I'd heard accounts of children pulling out the fur from their stuffed animals, which some parents considered to be an early sign of BFRB tendencies. Shirley sat up straight on the sofa and exclaimed: "You're joking?!" She got to her feet and said, "Wait 'til you see this!". She ran downstairs to Thomas' bedroom and brought back Rover, a faded and limp soft toy dog, whose body had been plucked to pieces, leaving only his head and ear fur intact. She gave him to me to inspect and poor Rover lay disintegrated in my hands. Shirley laughed and proceeded to tell me that Thomas had been given Rover the day he was born, and he had pulled out his fur for years. I asked her if she ever thought of that as the same as her hair pulling. She replied,

No, but I'll pay attention to it now. [Nervous laughter]. And he bites his nails, he's bad at biting his nails, very bad at biting his nails. But I don't make too big a thing out of that one. I just kind of think, like I remember my mum all the time. I remember being very self-conscious about my nails. So I think, it's just a thing that kids do, and it's a thing that kids grow out of, leave him to his own devices to stop it himself. He bites it right down to the quick and I'm just like, well that's what you get for biting your nails. Every now and again he'll say, will you help me with it and get me a pot of mustard or get me a pair of gloves, and I'll do that for him, but I don't make him do it. It's just what he wants to do with it. There you go, I'll have to watch out for Rover now won't I?

Shirley had not actively gone looking for information on trichotillomania before meeting me, and so our interview was also filled with her asking me questions about the condition. I initially regretted mentioning this comment about parents who



worried about BFRB tendencies in children, as it clearly sparked concern in her that I had not anticipated. But for the majority women with BFRBs I spoke to who had children, the risks of passing on their condition to their children were made clear. This was expressed through the language of fear and worry, and involved the anticipation of guilt, where parents said they would blame themselves if their children ended up having a BFRB. The fear of reproducing a BFRB in their children was not just mentioned by women with hair pulling and skin picking, but also by women who had not yet become mothers. During a workshop at the TLC conference in 2018, a woman shared this concern with the others in the session. She said, “I don’t want to pass this on to another generation. I want this to end with me”. Some of these fears were heightened at TLC conferences with new research focused on genetics, much of which confirmed that BFRBs run in families.

Anthropologists have highlighted the “embodied risk” involved in genetic advances within biomedicine (Lock & Nguyen 2010: 304). In particular Rapp (2000) has shown the way that risk in amniocentesis testing during pregnancy can shape women’s decisions on termination, where women feel a sense of responsibility for the “problem” (Rapp 2000, cited in Lock & Nguyen 2010: 312). In the case of Huntington’s disease, Cox & McKellin (1999) argue that risk is experienced intersubjectively within families, and is interwoven through “social, biological and temporal factors” (1999: 631). Building on these examples, we can see how mutuality of being, and the shared experiences of BFRBs, can embody potential risk in families. Due to the intersubjective experiences between parents and children, the risk of passing on a BFRB brings fear, worry and guilt, and these risks increase and change over time. This temporal aspect of mutuality of being was largely missing from Sahlins’ account, but was mentioned in one of the responses by Feuchtwang (2013), who says, “[mutuality of being] is distinguished by its own temporality: the temporality of generational reproduction” (2013: 284). I have demonstrated how childhood memories of parents continue to influence their hair pulling experiences over time, where ridicule and silence are remembered and still shapes feelings of shame in adulthood. Moreover, we see how

experiences of becoming a parent brings concern over the embodied risk of BFRBs, and the chances of “passing it on” to another generation. In what follows, we will see from Dhaya’s story some of the deeper complexities of mutuality of being that are not accounted for in Sahlins’ version of kinship; the reproduction of mutuality of being through mothers, to hair pulling daughters, to their daughters, but also the way that mutuality of being is deeply intersectional, involving gender and ethnicity as well as temporality.

Dhaya was born in England, and is the youngest of four sisters of Indian Sikh decent. At age eleven, when her hair pulling began, Dhaya was severely punished by her mother, including routine beatings. She told me that although all of her sisters were punished for different things, Dhaya’s hair pulling was considered the worst as it was viewed in the same realm as hair-cutting which is forbidden to Sikhs. Dhaya went against her family’s desires by marrying outside of the Sikh faith, and now lives with her husband and two daughters in London. Her relationship with her mother remained fraught, and she considered her to “trigger” feelings of low self-esteem.

My friendship with Dhaya blossomed after our first meeting in April 2015, and she invited me to stay in her family home on several occasions when I was in London. In the morning I would wake up early with the family and accompany her on the school run, attend playgroup with her youngest, and help cook meals. She told me one morning that she had to go through lots of counselling after having her first child in order to address her hair pulling. She said:

It’s just something about being a parent that makes you realise it’s not just you anymore, you’re responsible for another person, and I felt like I had to overcome it for them... also it’s bloody annoying because when they’re born, they come out with so much fucking hair! It’s like, you can’t get away from it. So they come out with a shit-load of hair, and then you get all the religious stuff from family to do with hair, and it’s like I’m in the middle and it’s all about hair. And the one thing that I’ve got just happens to be a disorder about hair.

On another afternoon while we were chatting in the living room, the girls were watching *Tangled*, the Disney rendition of the Rapunzel story, and her eldest daughter asked if her next birthday party could have a Tangled theme. Dhaya rolled her eyes at me and said, “Hair hair hair, it’s all about hair!” Her daughters had their own hair in long, perfectly maintained plaits, as Dhaya had chosen for them to keep their hair long in accordance with Sikh tradition. When I asked her if it was for religious reasons, she said, “It’s more that it’s what I’ve always known, like in my whole family I am the only one who has ever had short hair. That and I just can’t be bothered with the headache from my mum asking why I cut their hair”.

Dhaya’s annoyance as a mother with young daughters who were excited by Disney characters with unrealistic representations of hair; the pressure she felt as a mother trying to care for her children alongside her own mental health struggles, is revealed in the judgement from her own mother regarding the hair of her children. Dhaya’s example emphasises how different cultural expectations of hair affected her family’s responses to trichotillomania. The religious significance of hair for Dhaya’s family demonstrates that mutuality of being involves intersectionality and shows how important gendered, racial and spiritual differences might shape notions of care. Dhaya’s experience and her transition from “hair pulling daughter” to “hair pulling mother” illustrates the ways that life course events can alter perceptions of self and influence decisions in trying to overcome a repetitive behaviour. Her memories of childhood and her own mother, combined with new experiences with her daughters, shows the way that experiences of trichotillomania are intergenerational, and continue to affect relations between people over time.

Here I have shown how having a BFRBs can embody multiple risks for parents with BFRBs, both in their memories of how their parents dealt with their hair pulling, and in their concerns over how they might deal with their future “at risk BFRB children”. Interestingly, being a parent with a BFRB does not mean the limits of mutuality of being mentioned throughout this chapter do not apply, and even parents with

trichotillomania had the same concerns as non-hair pulling parents; that they would be unable to take the emotional pain away from their children. In the memories of harsh mothers, we can see a desire for love and affection in care practices which appear to be absent. Parents' responses to hair pulling children involve care practices that embody both love and harm, which stem from the limits of intersubjectivity. Parents feel they ought to be able to help, understand and control their children's emotional pain, as they feel it too, but they cannot, and so care becomes fraught and confusing. These care practices stay with people throughout their lives in the form of negative memories, but they transfer into the lives of people with BFRBs who become parents themselves, and as I will show, they shape both one's perception of self and one's ability to care for the self.

### **"Be your own mother": Reproducing Care**

One evening in January 2016, I phoned Dhaya to discuss my upcoming trip to London, and asked her if she had booked her flight to Dallas for this year's TLC conference yet. She was in the bath, and talked to me through speaker phone - she told me she was trying to take some time to "unwind" before her husband came home so she would be "less of a bitch". She said she was still undecided about the conference, and she was feeling guilty taking both time and money away from the family for her own benefit. After talking about it and explaining how supportive her husband had been and how he was encouraging her to go and not worry about the financial implications, she laughed and said: "Well it sounds ridiculous now I say it out loud!" Dhaya frequently felt that she didn't have any time for herself to do "self-care", and when she eventually did attend the conference in Dallas, she attended most of the workshops designed around self-acceptance and improving self-esteem, but continued to feel guilty for being so far from home.

Two years later, after I had become a mother myself, Dhaya and I sat across the room from one another at the TLC conference in San Francisco. As she started to speak, her

loud, familiar English accent comforted me from across the room. She had almost not been able to attend the conference that year due to finances, and she had been keeping me updated by telephone in the run-up to the conference. At the last minute, her mother had “felt sorry for her” and paid for her flight to come. I wondered if this was a sign of her mother’s prolonged guilt at being unable to support her daughter through her early years with trichotillomania. She opened up to the room about her experience: “I’m starting to realise that the unconditional love from a parent to child is so important and at the same time it falls by the way-side, and growing up I think I would have liked to hear ‘we love you no matter what you look like’. If my girls go through this, that’s what I can give them, what I didn’t have.”

When the session closed, the woman beside me said that Dhaya’s experience had really resonated with her. I agreed and told her I had been thinking about the same things. I briefly told this woman about my recent experience becoming a mother, and how my pregnancy had triggered the sudden urge to practice self-care. I started doing yoga every day, as well as deep relaxation and making serious attempts to keep my usual high anxiety levels from rising. I told her that it was not until I knew there was a baby growing inside me that I realised I wanted to control my anxiety and hair pulling. I made a conscious decision to look after myself with my baby in mind, and these steps all meant that I was pulling my hair less than I ever had before. I told her how this had made me realise I wanted to look after myself so I could look after my son, and I wished I had looked after myself in this way years ago. The woman responded, nodding thoughtfully and said, “You needed to be your own mother”.

This statement reiterates Dhaya’s own experience as well as my own, and helps to complete the argument that this chapter has built; mutuality of being is reproduced among families over time, and hair pulling experiences complicate the notion that mutuality of being always involves loving care. Care for Dhaya is intimately linked to her experience of love, which she felt was lacking from her childhood experiences in her relationship with her mother. Through Dhaya’s example we can see how memories

of mothers, influences her own experience as a mother. Her childhood memories subsequently shape the relationship with her daughters and her ongoing battles with herself in the search for love. Dhaya's experience of becoming a mother caused her to reflect on her own upbringing, and shaped her own care practices towards her children. It also changed her relationship with trichotillomania, and the responsibility of becoming a mother, meant she had to try and "overcome this for them". For Dhaya, "being her own mother" means being the mother that she wishes she had had, the mother who she wished had told her she loved her no matter what she looked like. We see that intersubjectivity changes over time, reproducing anxieties with her own daughters and concerns over how their hair will be perceived within the Sikh family. I experienced the reproduction of mutuality of being too. For me, the worry that my baby would absorb my anxiety in utero triggered a desire to overcome my life-long feelings of anxiety, to care for myself was to care for him at the same time.

## Conclusion

In this chapter, I have highlighted the ways that parents and children share a mutuality of being, in which intersubjectivity shapes parent-child experiences in important ways. I have built on current notions of mutuality in kinship studies, and shed light on some of its nuance and complexity. In particular, we can see how emotions and experiences of intersubjectivity are gendered, but also how these experiences reinforce gendered care practices. I also showed the ways that mutuality of being include complex intersections between gender, ethnicity and temporality. While parents clearly do share intersubjective experiences with their children, I argue that intersubjectivity simultaneously connects and separates kin. Mutuality of being does not lead to forms of care and love that are always harmonious and loving, and through close examination of how parents and children deal collectively with BFRBs, it becomes clear that care and love within families are sometimes quite fraught.

The different experiences highlighted in this chapter show how parents are deeply connected to their hair pulling children, sharing emotions like pain and guilt, and experiencing loss as they see it in their children. But importantly, this mutuality has limits, and it is in these limits that parents struggle to fully understand their children's experiences, and the reality of not being able to control their child's suffering. And so frustration and anger emerge, and with them come the complexities of care, involving both love and harm. In particular, the relationship between mothers and daughters, and the assumptions that loving care is expected within this bond, appears to heighten the suffering when care is not performed in expected ways. As I have shown, this darker side of care present in kinship relations has long-lasting effects, not only on people's relationships with parents, but also their relationships to themselves, and to their children. However, it is this expectation that families, and mothers in particular ought to be loving and affectionate in their approach to care, that makes the responses from mothers so painful for people throughout their lives. As a result, this longing for love produces a struggle to practice self-care and find ways to "be your own mother", which means to learn to love and look after yourself. But these experiences of the dark side of care also influence the relationships with the BFRB community that becomes "like a family", as will become evident in Chapter Four.

Families are often the first people that BFRBs are revealed and communicated to, and as I have shown these experiences are both positive and challenging. In the next chapter I will unpack the ways that the media reveals BFRB bodies, and how people negotiate the empowerment and risk involved in becoming "visible". In closing this chapter, it is important to note that much of what I have described here is related to the awareness and the public visibility of BFRBs in public culture. Building on the experiences the mothers who described the way hair pulling came from "nowhere" and who were unaware that "anything like this could happen to them", their sadness is also fuelled by the shock of having to deal with trichotillomania when they had never heard of the disorder before, and felt unprepared on how to handle it as a parent. This acts as a reminder of how awareness of BFRBs can directly influence the families of

those affected. In the next chapter, I will show how the lack of public awareness of BFRBs influences care and treatment options, as well as the way a “community” comes into view in different ways.





## Chapter 3

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### BFRB Visibility: Empowerment and Risk

It was December 2015, and Billie and I chatted before her hair appointment. We were having tea around the corner from Beverley's salon in Edinburgh, where she had been going for around a year. She said: "Did you know I did an article?" I had already been told by the salon manager that Billie would be a great person to talk to as she recently "came out" about her trichotillomania in the press. I asked her what the experience had been like. She described the process of being interviewed as "fine", and the photoshoot that accompanied it as "quite fun really". But she also said that she felt "weird" after the article was out, and found herself becoming defensive over her story, trying to limit the amount it was being shared on her Facebook page:

Even though I put it out there, and anyone could see it, I didn't *want* anyone to see it as well. It was like, someone I used to live with posted on my Facebook, 'Oh I saw your article in the Daily Record today' and I deleted her post, cause I thought, 'everyone else is gonna read that and then go lookin' for it'. [I don't mind] if people read the Daily Record and they see it, or they go online and they see it, but I don't want people snoopin' like purposely goin' to find out what this is all about. So I deleted the post, but I didn't put it on Facebook or put it out there myself. The people that know about it are my close friends, I don't wanna advertise it (Billie's emphasis).

We talked about her reasons for doing the article, and the process by which she came to that decision, which was a combination of financial incentive as well as the hope it might raise awareness and "help somebody else", but also help her to be more accepting of her disorder and feel less ashamed. I commented that despite all of these reasons, "It must have been a difficult thing to do". She said:

Maybe, I did it kinda whimsically and didn't really think about it, because now if you Google my name, it comes up, and now I'm kinda thinking, 'Oh god, anyone that I meet could just Google me and find that out about me straight away'. Whereas before, you don't tell anyone until they're *close*

*to you*, so maybe I didn't think about that at the time, but now I'm just like, "So what?" I don't really care if people find out [Billie's emphasis].

Billie appears to be caught in a dilemma between wanting to raise awareness, and being concerned by her lack of control over who might see the article. This dilemma opens up the challenges of making BFRBs visible, and how public awareness can bring both empowerment and risk. This chapter will explore the experiences of people who have shared their stories with the media. I will unpack the factors that contribute to this process of revealing and demonstrate the difficulties of "coming out" to the public. I reveal how BFRB visibility is tied to certain power relations within the BFRB community in the United Kingdom, which make certain treatments - and their users - visible over others. In this discussion, I focus specifically on the services offered by Beverley's salon, and reveal some of the challenges faced by the women who use them. I show how women at Beverley's negotiate the balance between revealing and concealing, and how their experiences of coming out highlight the risks associated with techniques of concealment. The hyper-visibility of Beverley's clients in the media has triggered tensions surrounding recovery within the BFRB community, and illustrates gendered and racial inequalities in the public presentation of trichotillomania. This chapter acts as a contrast to Chapter Four, which will go on to show a resistance to these BFRB narratives through alternative forms of coming out.

### **Visibility and Awareness**

Throughout my fieldwork, public representations of BFRBs in the media frequently caught my attention. News articles were circulated within Facebook support groups, and television and film documentaries discussed. During interviews with women, they frequently expressed their frustration with the lack of public awareness on BFRBs. Comparisons were made with other mental health conditions that have become increasingly recognised over time, and there was a wish that BFRBs could be better understood by the public. In a conversation with Cara, she said:

If we can raise the profile and the awareness [of BFRBs] it would be a real relief to people who have the condition who'd be able to be more open about it, because it means that we could say 'I have trichotillomania' and people would immediately know what that is without us having to explain it all the time which can be very difficult.

My first two chapters have outlined a lack of understanding of BFRBs among sufferers themselves, as well as among their families and loved ones, who all struggle to make sense of these behaviours. In Chapter Two, we saw the way people living with BFRBs feel frustrated when family members “just don't get it”, and the ongoing challenges of trying to communicate their experiences with the world. We also heard how parents complained about “not knowing” about trichotillomania before they saw it in their children, which had a direct effect on families' ability to deal with BFRBs. This lack of public knowledge about BFRBs was also noted by people living with them one of the main reasons why people sometimes spent years thinking they were the “only one in the world” who pulled their hair or picked their skin - an important factor in the isolation and confusion that surrounds these conditions. For these reasons, many people that I spoke to wanted BFRBs to be more visible in the media, and complained that there wasn't enough “out there”. Some people told me that the desire make BFRBs more visible was one of the reasons that they were attracted to my research. Sharing their experiences with a researcher provided an opportunity to make BFRB experiences recognised and to change existing perceptions about their condition to the public without coming out. The quality of current representations of BFRBs was often questioned, as many people felt that the way in which trichotillomania was represented reinforced the stigmatising aspects of the condition. Therefore, as evident in Billie's example above, hopes and fears around coming out coincided with a lack of trust in media representation.

The balance between empowerment and the risk of coming out has been explored by anthropologists, predominantly in examples linked to HIV/AIDS (Hardon & Posel 2012) and LGBTQ experiences (Gray 2009). Focussing on youth experiences of reproductive and sexual health, Hardon & Posel explain how HIV/AIDS activism has led to

widespread acceptance for the illness, based largely on the positive notion of overcoming the “burden of secrecy and shame”. They summarise the view that secrecy in this context has been framed as “social death”, comparing HIV/AIDS stories of coming out in the same liberating rhetoric as LGBT “closet” metaphors (Hardon & Posel 2012: S2). The empowerment of HIV/AIDS disclosure has also been linked to ideas of therapeutic citizenship, whereby people living with the illness are only able to access care following a confession (Hardon & Dilger 2011). We see here that people negotiate visibility in different ways that involve being revealed and concealed at the same time, and this negotiation creates risk and opportunity.

The media has changed notions of coming out, and subsequent illness visibility, and Gray (2012) has examined its role in a rural American LGBT community. She argues: “If visibility is imagined to be the road to acceptance for LGBT-identifying people, much of that recognition circulates through representations in the media” (Gray 2009: 11). Gray focuses on what she calls “new media” which includes online spaces, but I mostly address news articles and documentaries on trichotillomania. These forms of media cross online and offline boundaries, and are sometimes viewed in printed press, but they are “shared” in online Facebook support groups. Their “visibility”, then, is both revealed and concealed, being shared widely in certain spaces, but kept hidden in others. In the examples that follow, I will describe some of the fears around the potential for these articles to be shared widely, and the imagined reach that their online form allows, which posed both benefits and concerns.

### **The Hair Pulling Spectacle**

During an interview in London with Sandra, she told me about the first time she came across “the name”. She said, “I was in a doctor’s surgery, and I was flicking through a magazine, and saw this picture of a bald Barbie... and was like: ‘Oh my god that’s TTM [trichotillomania]’”. Sandra found the image of the bald Barbie as a recognisable symbol for “TTM”, but others had questions about the purpose of certain media

representations. Catherine has had trich since she was a teenager, and works as a researcher in psychology. She spent years looking for her own information about trichotillomania. In a conversation we had in October 2015, she mentioned her frustrations with the articles she had come across in the past: “In the press you get this thing that will say: ‘Woman in Manchester admitted with massive hair ball in stomach’, and you think, did she give her permission? It’s probably something she’s kept a secret all her life, and then she’s outed in the paper!”

Like Catherine, I had also seen numerous articles about “hair balls in stomachs” when I did online searches for articles on trichotillomania, and was surprised by the number of these shocking articles that had been written about a seemingly “rare” condition. As I mentioned in Chapter One, the personal rituals and embodied urges that people experience with hair pulling and skin picking are highly sensory, and often feel inexplicable to the people who do them. The act of eating hair after it has been pulled has been given its own name in the DSM, trichophagia, and is considered to be rare in comparison to trichotillomania. The media attention given to trichophagia, and especially what happens when hair balls build up in the stomach and have to be surgically removed, as well as the photographs that support these stories, are quite disturbing. In my observations of these articles, I found myself saddened and frustrated at the lack of attention given to the disorder itself; the surgery to remove the hairball was often treated as the end of the problem. Worryingly, many of these stories are about young women or girls, and concern for their ongoing lives with trichophagia seems to be missing. In one of the articles about an eighteen-year-old woman from Kyrgyzstan, it said at the end: “Ms Alekseeva will be go home with her parents at the end of the week, and has promised to stop chewing on her hair” (Dodds 2014). A more recent article highlighted the seriousness of trichophagia when it described the death of a sixteen-year-old young woman who suffered organ failure due to blockage (Dovey 2017). While this story could have been a good opportunity to raise awareness around BFRBs, and to highlight the potential life-threatening risks of trichophagia, the news coverage failed to do so. Fox News included this story in their

list of “Weirdest Health Stories of 2017” (Fox News 2017), further highlighting this story’s potential entertainment value. The idea of hair pulling experiences as entreating was mentioned by Cara when she told me about her annoyance that trichotillomania had been featured on the show *Embarrassing Bodies*:

You’re treated like a freak, it’s like, “Oh look at this weird thing that this person does” you have that kind of voyeuristic angle on it, I don’t think that helps the people [on these shows] feel any better and I don’t think it actually informs people who are watching that, because it’s kind of entertainment value rather than a more kind of scientific perspective, so I think the coverage at the moment is poorly lacking [Cara’s emphasis].

An important factor in these representations is the use of images to show the extreme and shocking damage that women have done to their bodies. As Chapter One detailed, concerns with revealing the BFRB body are linked to the “unusual” nature of BFRBs, and fear of reactions to bodily urges and feelings. We also heard how people are deeply reluctant to reveal the BFRB body. But media representations simultaneously reveal the bodily damage, and emphasise the “weird” process of how these bodies have become “marked” or “damaged”. Increasing the visibility of BFRBs thus creates a conflict; on the one hand people wanted the world to know about the embodied urges of their BFRBs; but on the other, to see oneself in these sensationalist exposés increased feelings of shame and embarrassment. The risk of making BFRBs visible highlights the risks associated with revealing the BFRB body and the fear of stigma that this can create for people.

### **“Girls on the Pull”**

In my analysis of media features on trichotillomania, I also found evidence of the uncomfortable emotions that revealing the BFRB body could foster. One of the few documentaries about trichotillomania was aired on Channel 4 British television in 2011. *Girls on the Pull* is a short documentary that many of my interlocutors had watched, and it was often criticised in support group conversations for the way it

portrayed the condition. The film begins with images of strands of hair falling, as if being dropped from a distance. The documentary follows the stories of three white women, and also includes an expert interview with Beverley. All three women who have trichotillomania in this documentary at some point show the viewer their “real hair”, removing their wigs and hair pieces to reveal shocking damage on which the camera focusses closely. For one of the women, this exposure is clearly distressing, as she faces the mirror, the camera positioned behind her directed straight at her biggest pulling spot. As she looks at herself in the mirror she touches the thinnest part of her hair and says quietly: “I’m very conscious that this is a weak area, so it doesn’t feel great to have my back to you at all. I don’t let many people see me like this” (Girls on the Pull, 2011, 05:00-05:11).

The level of discomfort experienced by the woman in this film, was also expressed by my interlocutors in Chapter One when I described their use of techniques of concealment. Revealing the BFRB body is something that is not only avoided with strangers, close family members, loved ones and from other people who don’t have BFRBs and might not “get it” - it was also something that was kept hidden from people *with* BFRBs. Despite the close bonds that I made with many of my informants during fieldwork, there were very few people who ever showed me photographs of their hair loss (at any point in their lives) or ever removed their make-up or wigs for me to “see”. Needless to say, I never considered asking anyone to reveal themselves to me. Instead, it was very unexpected when a few people did reveal their hair loss to me, and I was surprised by their willingness to share such a private thing. Therefore, if people with BFRBs do not feel comfortable to reveal their hair loss or scars to others in the community, we can see how revealing it to the media publically might instil elements of worry and risk.

The power of the media to reveal BFRB bodies was reinforced to me when I was approached with two opportunities to share my own story with a student documentary filmmaker during fieldwork, and by STV in an interview post-fieldwork.



Both of the producers of these separate pieces asked specifically if I had any photographs of when my hair loss had been at its worst. At the time they seemed to respect my decision to decline providing these images. However, I noticed that both pieces included visuals as part of other people's stories, which caused me to ask why it is necessary to include visual evidence of a disorder like trichotillomania. I argue that the media's sensationalist focus on trichotillomania is deeply connected to a particular fascination with the unusual things women do to their bodies.

Warin (2004) has examined a similar account of the sensationalist way that anorexia is presented in the media. She says that images of extreme skinny bodies reproduce "the visual spectacle associated with emaciation, and ignores the profound embodied sensations of power and suffering which are central to experiences of anorexia" (2004: 95). As I have also shown, the embodiment of BFRBs involves complex sensations that go far beyond the visual, and so the sole focus on physical hair loss and scars reduces BFRB experiences to simply cosmetic issues.

Like eating disorders, trichotillomania is highly gendered, with research suggesting women are affected more than men. Media representations of hair pulling therefore reinforce and reproduce gendered assumptions about trichotillomania as a "white female disorder". I argue that this overwhelming presence of the white woman with trichotillomania that features so frequently in UK press, reinforces normative beauty ideals by revealing of certain types of people, and concealing others who do not fit this image.

### **Beautiful Bald Barbie**

The media representations of trichotillomania in the UK are clearly influenced by the power of Beverley's salon as a leading figure on TTM, and can be examined through the gendered beauty norms that permeate Beverley's salon and its services. When Sandra found the advert for Beverley's salon which featured the image of a bald Barbie

doll, for her, it immediately signified TTM. But the image of a bald Barbie does more than grab the attention of people reading a magazine or newspaper; but it is laden with the cultural meaning of women's hair. The article that Sandra saw was featured in a magazine 15 years ago, but since, bald Barbie has become a marketing phenomenon to help girls cope with the results of cancer treatment. Also called "chemotherapy Barbie", the Ella doll was launched in 2012 as part of a campaign with the tagline "Beautiful Bald Barbie!" (Murphy 2012).



Figure 2: Beautiful Bald Barbie Campaign

The inclusion of bald Barbie reflects an ongoing development by the Mattel company, as the brand has introduced many new dolls over the years to expand its appeal to a multi-cultural market. Despite the growing selection of dolls and the growing range of girls they are targeted to, Barbie's iconic body and hair image continues to reflect the beauty ideals for Euro-American women which resonates in the images of TTM in the press. In my review of news articles online between 2015-2016, many described the experiences of brides with trichotillomania who received new hair for their wedding day. Headlines included:

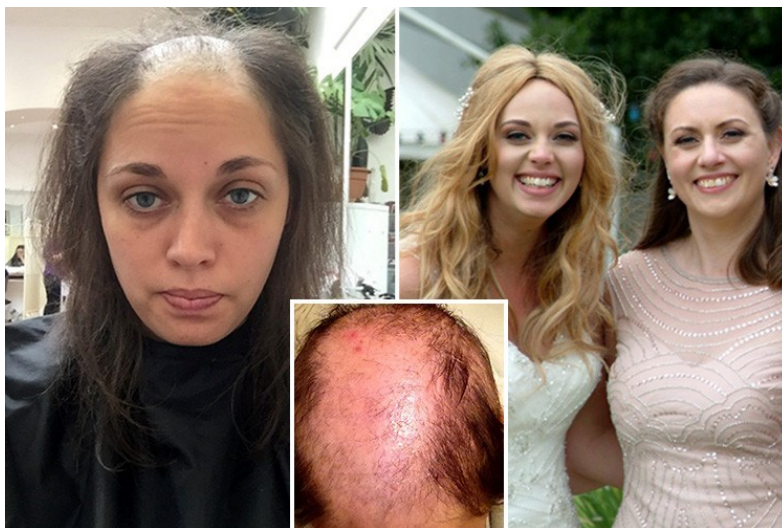
Bride-to-be addicted to pulling hair out walks down aisle with flowing locks after groom buys high-tech hair piece (Martin 2015, Figure 3)

Woman whose hair-pulling addiction left her BALD finally marries her childhood sweetheart after revolutionary treatment to regrow her locks (Brennan 2016, Figure 4)

“I FELT LIKE A NEW WOMAN” Bald bride-to-be finally ties the knot – with gorgeous long locks – after overcoming her rare hair pulling disorder (Parry 2016, Figure 5)



*Figure 3: Photographs of trichotillomania in The Mirror*



*Figure 4: Photographs of trichotillomania in The Daily Mail*



*Figure 5: Photographs of trichotillomania in The Sun*

Analysing these articles through a feminist lens allows us to question the way that women seek out heteronormative beauty ideals, and highlights the ways that baldness does not fit into this framework. In particular, Ahmed (2017) has critiqued the idea that women are told from a young age that their wedding day will be “the happiest day if their life”. The inevitable disappointment that these unrealistic expectations produce is what she calls “gender fatalism” (Ahmed 2017: 48). Although we can clearly see aspects of gender fatalism in the way these news articles are framed, it was clear from my examples in Chapter One that women look forward to their future wedding day. They also expressed a desire to have their own hair on this special day. Wedding days are important in the life course and they are imagined in relation to women’s aspirations for how they want to look on their wedding day. However, gender fatalism also encompasses the disappointment that women might feel when this day comes, and their expectations of happiness are not met. In Billie’s example, she told me at the start of our conversation that her hair system was “the next best thing” to having her own hair on her wedding day, but as our interview progressed it became clear that she had been experiencing increased feelings of anxiety and depression since the wedding, and since having her hair system fitted. This surprised me, as I too assumed that having new hair for her wedding day would make her feel “happy”. I asked her where she thought those feelings had come from. She replied, “I think it

might be that I had something massive to look forward to in the wedding, and that's gone... and I think it is a bit of anxiety that I couldn't pull my hair and that's naturally turned into a little bit of depression". The expectation that a wedding will bring happiness for women means that Billie's depression following this moment appears out of the ordinary. The newspaper articles reinforce gender fatalism, by exaggerating the expectations of how women ought to look on their wedding day. Female baldness does not fit with this image.

The question of what baldness represents in women sometimes came up in discussion with my female informants, with several women referencing the time when Britney Spears shaved her head in public. The event happened in 2007, and was talked about as the moment that showed the "unravelling" of her mental health, and her "downward spiral". My informants mentioned this with sarcasm and resentment: "It's like when Britney shaved her head, everyone was like '*whoah* she must be *really crazy!*'". The press talked about this event in a way that highlighted the relationship between hair loss and mental health, as if the only reason a woman would choose to become bald was through madness. Here we can see similarities between how the media presents trichotillomania and what Martin (2009) has described in her analysis of the representations of bipolar disorder in media and advertising in America. Martin says that mania in women continues to be reinforced in negative terms, while manic men are made out to be "valuable" and productive as modern assets in the capitalist marketplace (2009: 216). She says, "the energetic force of mania makes it difficult for a woman to pull off being manic while keeping her female identity" (Martin 2009: 212). In the same way that gender shapes the way media frame mania in America, bald women in the UK press are described as either "mad" or "sad".

The sadness of women losing their hair was also visible to me in a news article about Beckie0. Rebecca Brown, or Beckie0 as she was called during my fieldwork, was a well-known trichotillomania sufferer and YouTube video-blogger who had become famous in trichotillomania networks. Beckie0 has been making YouTube videos since she was

a teenager, documenting her journey with trichotillomania. Over the years she has presented her struggles with hair pulling, and her ongoing aspirations to grow back her full head of hair. At different points when her hair loss has been at its worst, she decided to shave her head to “start afresh”. In one video, she shows the whole process of shaving her head, through which she explains how difficult this moment is for her, and eventually shows herself crying while buzzing the last of her hair (TrichJournal, YouTube, 2016). Her story was picked up by the UK press in January 2016 with the headline: “Heartbreaking video shows brave 23-year-old shave her head to combat compulsive hair-pulling disorder” (Ryan 2016). Around the same time, Beckie was asked to give an interview on BBC Radio, which I tuned in to listen to. The radio presenter, for the sake of the listeners, described Beckie as “a really stunning young woman”. Whether this was a comment of surprise from the presenter, or an attempt to help the audience visualise Beckie, to me, it felt unnecessary to point out her appearance, and also reinforced the above headline - which suggests it is “heartbreaking” for an otherwise “stunning” woman to lose her hair. For many women with trichotillomania, the option of shaving their heads was thought of as a welcome relief from pulling.<sup>14</sup> A few people that I interviewed had chosen to deal with their hair pulling in this way, but others worried about the social stigma they might receive, as discussed in Chapter One.

Ultimately these articles suggest that women need hair to be beautiful and happy. Despite the Barbie campaign, and its claims that bald is “beautiful”, the news coverage I have described sends a message to women with trichotillomania that they still need hair to have the “wedding of their dreams”. In contrast, however, hair loss in men is not viewed in the same way. I will now contrast expectations of beauty and hair for men with trichotillomania, who are almost completely hidden from the public eye.

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<sup>14</sup> As I have mentioned, trichotillomania can affect any part of the body, so this option only worked for women who pulled from their scalp and not eyebrows or eyelashes.

## **“Baldness can be attractive in men”**

Trichotillomania is not just a female disorder. Comparable to experiences of eating disorders, it is thought to affect women more than men (Duke et al. 2010), although most of the statistics for BFRBs lack credibility due to the silence of those who suffer from them, and the unlikeliness of admitting their problem to professionals. Interestingly, childhood cases of trichotillomania are mostly equal between girls and boys, but hair pulling in adult men appears to scale off (Grant & Christenson 2007), which may be caused by secrecy and lower levels of help-seeking, rather than the likelihood that they have overcome it. While I did have the opportunity to meet several men during my fieldwork and hear about their experiences, I was disappointed that I couldn't talk to more, and it appeared from my observations that men living with trichotillomania were silent, rather than absent. When attending the TLC conference in 2016 I asked one of TLC's leading researchers, about the absence of men at these events. He responded:

I believe there is something both biological and/or cultural, because hair in women is, you know, it's obviously one of the most important indications of beauty, cultural power, you know, hair products and hair salons and hair styles and hair, it's so unified with the concept of women. Now with men... it doesn't seem to be as central. So on the cultural side... generally looking back in history, you see a lot of indications that hair in women and femininity are one and the same. So hair loss in men, well men lose hair, where women aren't supposed to lose hair, so it's tragic when a woman loses hair and more noticeable. We understand that men lose hair and we understand that baldness can be attractive in men, but less so in women, it's usually more of a statement and not considered beautiful. If any man came home and the woman he loves suddenly shaved her head, they'd probably freak out for the most part, you know?

The assumption here is that men with hair pulling suffer less than women. This is based on the belief that men do not value hair in the same ways, and are not *valued for* their hair in the same ways, thus they do not feel as ashamed to lose it. The quote summarises that hair is a central marker of “beauty” and “power” and “femininity” for women, but for men this is not so “central” to masculinity or identity. He reminds us

that “men are used to losing hair” so therefore should not be so upset when they do. From my observations, I believe it is this naïve assumption that causes men with trichotillomania to be overlooked and underrepresented.

During an interview with Morris in a Camden café in March 2016, he told me how he had managed to keep his trich hidden by growing his hair long to make the bald spots less visible. Morris was an Oxford University student in his early twenties, who had floppy dark brown curls that framed his head. When we talked, drew attention to his hair style, pointing out his target area for pulling, I noticed it was slightly shorter on one side than the other. He talked about how he had attempted to stop pulling through varying hairstyles, trying to keep it very short to make it more difficult to pull out, but in the end he found hiding it easier than stopping. But the reality of losing his hair later in life to male pattern baldness concerned him, and during our interview he mentioned that in his family his father was the only man who hadn’t lost his hair. He said he hoped to stop pulling it out before then, as it would be really “sad” to start losing it before managing to overcome trich.

In Chapter Two we saw how gendered beauty norms came up in conversations with parents who were caring for their daughters with trichotillomania. Mandy suggested that it is easier for a man to hide hair pulling due to society’s acceptance of boys with short hair in comparison to girls. However, the ability to keep hair loss hidden is not the only marker of shame, and so measuring suffering in terms of visible loss is not always an accurate representation of someone’s experience. It is also true that despite male hair loss being normalised, the shame associated with male pattern baldness has not diminished. One indicator of the level of stigma that men experience from hair loss could be reflected in the immense demand for hair transplants and treatments in an industry that continues to flourish (Tarlo 2016). Like Morris, other men I spoke to did not seem to suffer *less* in any way, but instead experienced hair pulling in different ways due to their own anxieties about hair and how they ought to look. Men were also less likely to attend support groups and less interested in meeting other people with



trich, knowing that they would be in the minority as men. A few of them told me that they did not find these spaces “useful”, but it should be considered that men with trichotillomania do experience the double-stigma of having a “female” disorder - much like men with anorexia (Morgan 2008) or breast cancer (Donovan & Flynn 2007). These experiences of stigma likely have an effect on help-seeking and the ability for men with hair pulling to feel part of the biosocial BFRB community. Media representations of TTM that focus on Beverley’s salon are implicated in reinforcing this image of the disorder as “female”. If men with trichotillomania - or parents of hair pulling sons - go searching for information on this condition in the hope of finding treatment, what is the likely impact of finding numerous news articles and images of women on their wedding days who have been saved by revolutionary hair extensions? Examining the ways that people with trichotillomania are made visible through the press, reveals the way that gender can shape both experiences of BFRBs, and access to the BFRB community. In my next section, I continue to unpack the hyper-visibility of Beverley’s clients in the UK media, while examining the role of race and the “white female TTM sufferer”.

### **“Black Girls with BFRBs”**

Like men, people of colour are hidden from view in the public image of trichotillomania, and they were also largely absent at TLC conferences that I attended there in USA. Among my group of interlocutors, all were white except for two women of colour, Dhaya and Robyn, despite the fact I spent much of my time in London with all its diversity. But I was continually struck by how white BFRB spaces were, especially the TLC conferences. Dhaya, often joked about this when she was at the conference with me and they asked her to be photographed. She said: “They get double diversity points for having me in the brochure, cause I’m British *and* I’m brown”.

The absence of ethnic minorities in the BFRB community was something that interested me, and in my interview with one of TLC’s SAB members, I asked him about

this. Being one of the few people to do research within the African American community, examining hair pulling experiences within a college population, he told me about his findings. He said: “The numbers are not drastically different, but the impact on their life was virtually non-existent”. He went on to explain that: “African Americans are less likely to seek out professional help”; and that they are also “more likely to go to the hair salon or barbers for a hair problem”. Further, he noted that: “they have a wider acceptance of different body types and hair types in the African American community than in the Caucasian community”. But the thing that he found the most interesting from his research was idea of “resilience”. He said:

Perhaps built into the African American experience and perhaps other minority experiences is a kind of resilience that makes them more likely to just pludge [sic] ahead with life and not necessarily have so much of their identity focused on what isn’t in most cases a life-threatening problem, it doesn’t threaten your life, it spoils your life basically, but if you have to do other things that are important then maybe you just have to overcome that just like you overcome other issues.

He went on to describe this resilience of minorities as an admirable characteristic. He praised African Americans for being able to cope with a higher level of suffering and life problems, and suggested this ability to deal with suffering was a reason why hair pulling wouldn’t seem “so bad”, since they had already faced a great deal of discrimination and lack of opportunity in American society. This common sense approach to suffering is both short-sighted and problematic; but it brings together critiques of “Black resilience” in the context of hair and health.

Bridges (2011) has shown how the idea of resilience in Black women’s experiences of pregnancy can lead to inequalities in care. Her ethnography of New York City’s “Alpha Hospital” she connects these inequalities of care to a long history of biomedical injustices and racism. Bridges draws on Hoberman’s definitions of the “obstetric hardiness” of Black women, which he argues had been used to justify explanations that Black women experience less pain in childbirth (Hoberman 2005, cited in Bridges 2011: 117). The accounts from Alpha doctors that Bridges presents highlight

underlying racism that feeds into ideas of Black resilience and “racial biology” that perpetuates the cycle of different care for different groups who are considered to be “higher risk” of diseases. Bridges argues that assumptions about “natural” differences in Black people have led to a continuation of racial stereotypes about health in biomedical frameworks of disease and has allowed racist views of health professionals to perpetuate. In the same way that Black women are thought to feel less pain in childbirth due to being resilient, the quote from the clinician above follows these racial assumptions by saying that Black women’s resilience makes them less likely to suffer in the same way as white women with trichotillomania. This argument also ignores the underlying racism inherent to Black women’s experiences of hair care which has historically compared them to ideals of “white beauty” where Black women are denied the right to “share the pedestal of transcendental beauty with white women” (Young 1999: 79). Like the men described above, the idea that Black women suffer *less* from trichotillomania due to their lower expectations of having “real hair”, or that they have bigger things to worry about, undermines their experiences of trichotillomania and makes excuses for their absence or exclusion from the BFRB community.

Despite the troubling comments from the clinician above, I did notice changes in TLC’s conference diversity over time. Of the three conferences that I attended in 2015, 2016 and 2018, the most recent in San Francisco was the most diverse, and there I was given the opportunity to gain insight into some of my ongoing questions into the multi-racial experiences of BFRBs. In the gap between the conferences I had attended, TLC had clearly made great efforts to expand their outreach into harder-to-reach groups, and the push for diversity was seen in their planning of a “Special Interest Group Meeting” in 2018. I left another session early to attend this meeting, keen to hear what was going to be discussed.



*Figure 6: African American women attending the TLC Conference in 2018*

The ballroom had been set up with 8-10 round tables, each being marked out for a different “special interest group” to which people were encouraged to assign themselves and some of the categories I noted were “African American / Black”, “LGBTQ+”, “Asian”. I quickly took a seat at the African American / Black table, and as others joined me, I asked each of them if they minded me sitting in. I explained who I was and my interest in finding out more about the Black experience. One of the women said she was pleased that I had asked, and they agreed they were happy for me to stay and listen to the conversation. One of the women wore a t-shirt that read “Black girls with BFRBs”. I was not the only white person at the table; I was joined by a white female TLC staff member, and a young queer man who was on TLC’s Young Adult Action Council. He asked to join the table since the LGBTQ+ table was overflowing.

The conversation at the table centred around care, and how difficult it was to access therapy that was suitable for BFRBs, and the stigma around therapy in the Black community. They all agreed that typically, “Black folks don’t go to therapy” as this was

considered “white people shit”. It was mentioned that women do classically seek help for hair issues at hair salons, and would always go there in the first instance rather than the general practitioner. But it was also recognised that cosmetic treatments for covering hair loss only worked on the surface and that they highly valued CBT and talking therapy as well. Their main issues, were with the representation of therapists, and they said that if people in the Black community were to go to therapy, they would feel more comfortable with a therapist of colour. The difficulty, then, was finding a BFRB-trained expert who also meets their representational needs. The small number of scholars who have conducted research on trichotillomania in the Black community have reconfirmed these observations, noting that the because trichotillomania is not considered “a black behavio[u]r”, African American women who engage in hair pulling behaviour may feel less connection to the Black community (Neal-Barnett & Stadulis 2006: 757). While this study gives limited context to the topic of community, it shows the increasing need for attention to intersectionality in the context of the BFRB community.

My observations of who is absent from the public image of trichotillomania has revealed the idea that certain types of people are considered to suffer less from BFRBs. Men are thought to be used to the idea of losing hair, and Black women are a meant to be accustomed to having false hair; making both groups less vulnerable to hair loss experiences. In contrast, it is “heart-breaking” and “tragic” when a young white woman is forced to shave her head. We begin to see that the BFRB community is not all-inclusive. The hyper-visibility of Beverley’s salon not only promotes the image of the “white female TTM sufferer”; it also reveals tensions surrounding recovery in the BFRB community.

### **Beverley and the Angels**

Beverley’s hair studio is tucked away in the west end of London, hidden in a classic Townhouse between a run-down retail unit and a high-end nursery. When I visited for

the first time in June 2015, I immediately noticed the cars parked outside the building; a white Porsche, a new BMW and a baby blue Bentley convertible. When I entered, the staff at the reception area were welcoming; attractive hostesses smiling, all wearing dark high-waisted pencil skirts, fitted purple shirts and headsets. They had smooth neat hair and flawless make-up. I was invited to sit in the lounge as I waited for Beverley. Comfortable cream armchairs were surrounded by blooming orchids, elegant lighting, sparkling décor and large mirrors. On a coffee table there was a display of recent Beverley newsletters, which featured an update on the Edinburgh studio, and information about upcoming events, one of which was called “Cocktails and Cupcakes - TTM Night”; a chance to meet other people with trichotillomania with guest speakers. I flicked through a portfolio of laminated letters of thanks from clients. One letter read; “Thank you Beverley and the angels. You have changed my life”.

I waited for around fifteen minutes, until Beverley welcomed me with a warm hug just like she did a few days earlier at the TLC workshop at Kings College London. We headed up the stairs to the main studio. Beside the “events lounge” was a professional coffee



*Figure 7: Beverley's Salon Waiting Area*

machine with shiny glassware in an area that looked like a bar. Beverley commenced my studio tour immediately, as we moved quickly through the space. She introduced me to the team, and proudly showed me around the toilets. All of a sudden she stopped, seemingly disappointed, and explained that there is usually classical music playing. Exerting authority, she proceeded to ask several people to turn the music on in the “loos”. Eventually she shouted after Jack - the studio manager and her own son

- to turn the music on. He paused from his busy trot around the studio to tell her it wasn't working, and so she rolled her eyes and continued my tour.

Looking around at all the women having their treatments, Beverley stalled at a woman who had just had her new hair system fitted; insisting that I have a close look at her head. I smiled at the woman through the mirror and she smiled back. As I peered at her head, unable to tell the difference between the system and her real hair, I told her it looked beautiful. We turned another corner and Beverley spreads out her arm motioning to the additional 6-10 salon chairs busy with clients. Pink screens separated each chair to allow for privacy. We climbed up to the second level of the studio where another 8-10 seats are available for clients. Beverley began a conversation with the staff about the new purple panels on the wall, which apparently used to be white, were now bright purple, but were meant to be lilac. She said "It's Jack's fault, you see men don't see colours in the same way that women do – he thought the cushions were blue when we all knew they were grey!" We laughed at this comment and Beverley and I headed back downstairs to take a seat in her office. It was a large room decorated in gold, white and pink. There was a whole wall painted with gold glitter beside her desk, photographs surrounded the space and thank you cards adorned the walls. Plants and ornaments were numerous and impressively large. I sat across from her at her desk and she asked me to tell her "my story"; "Tell me everything, about your hair and your life!" She complimented my long curly hair and reached her arms up to touch her own hair, cocking her head back gracefully. She explained that she had spent all morning in the car and had barely had time to brush her hair. She untied her long straight blonde locks and proceeded to brush the, letting her hair fall loosely around her shoulders; suddenly perfect. As she brushed, she talked non-stop, chattering excitedly and laughing: "It's all fake of course, just like the rest of me!" I couldn't quite believe that it was all fake, since it looked and responded just like "real" hair. She asked further questions about me, and if I had hair extensions. I touched my hair anxiously, examining the split ends, and told her I didn't. She scoffed with laughter and said, "I'd buy it all from you! I'd cut those curls right off you!" I laughed nervously, feeling guilty

for having so much hair, knowing that she had been bald from alopecia since she was a child.

In my interview with Billie at the beginning of this chapter, she told me that the main reason for her deciding to go to the press was that she got “paid for it”. During my conversation with Billie, I found out that Beverley’s salon offered credit towards her hair treatments if her story got published in the press. Finding out this information, suddenly explained the similarities of the articles I had seen. I had noticed that in the majority of news articles the sufferer was only female; the sufferer was always white; and they frequently referenced Beverley’s salon. From what I have already described, the focus on white women in these articles who overcome their hair pulling due to a “revolutionary” system that helps hair “regrow”, is more representative of this treatment model, than of the wider experiences of trichotillomania. Beverley is someone who has the authority to speak on behalf of TTM and to make people visible. But at the same time, Beverley’s influence reinforces female beauty norms and the existence of hair as both a commodity and a cure; a notion that many people in the BFRB community disagree with.

In October 2015, I attended a group meeting with some of the people who had attended TLC’s first ever London workshop in June. It was a small group of people, including Dhaya, and it was the first of many group meetings that would eventually become the London support group. We met for lunch at the National Theatre in London’s Southbank. As it often did in these group meetings, due to her reputation, the conversation turned to Beverley. Dhaya had very strong feelings towards Beverley, as many people did in the community. This conversation was about an article that had been shared online a few days earlier as part of “BFRB awareness week”. Previously “Trichotillomania Awareness Week”, October 1<sup>st</sup> - 7<sup>th</sup> had recently been re-named by the TLC Foundation to include people with skin picking as well as other BFRBs. However, the article (BBC 2015) called the awareness week “No Pulling Week”. Those who had seen the article, explained the different name to the others at the group



meeting. Dhaya couldn't hold back her outrage. She said: "It's bloody ridiculous, I mean you wouldn't call an anorexia awareness week "eat something week!". Dhaya's comparison here is important, and for her, "No Pulling Week" showed a lack of understanding of the complexities of the condition, and the strength of urges that I have detailed in Chapter One. But for Beverley, the notion of being "pull-free" is essential to her ethos of treatment for hair pulling, as it complemented the type of services she offered.

The hair system that Beverley has developed is designed to cover the trigger areas on the scalp, and is woven into existing hair so it cannot be removed between appointments. It will usually be worn for over a year, being tightened ever six weeks and taken off to wash and inspect the hair underneath every six months. In this time, the hair should regrow underneath, with the idea that when the system is finally removed, hair should have regrown fully and hair pulling urges should have ceased. During my fieldwork, I met one woman who had successfully been able to stop pulling in this way. Others I spoke to had reduced the amount they pulled drastically due to the system being permanently on their head, although many felt their urges so strongly that they were still able to get their fingers underneath and pull between gaps. As we saw from Annie's experience, having the hair system on *increased* anxiety as she was unable to pull hair, which usually helped her to relieve tension. Wearing the system also brought an element of fear about what might happen when it was removed and they finally had a full head of hair. Many knew that their urges had not lessened and worried that they would simply pull it all out again. Importantly, investing in this hair system is big financial commitment; given the length of time it had to be worn, as well as the duration of time spent at appointment and follow-up appointments; it was described to me as the same as "having a second mortgage".

Tarlo (2016) has described hair care as an investment, and as someone told her, "[hair is] like a house. If you invest money in a house you better look after it! It has to be maintained." (2016: 140) This maintenance often requires "large investments of time,

money and discomfort” (2016: 142). But while hair is clearly an investment for many women, Tarlo also reveals the vulnerability of women who experience hair loss. She describes the story of Sunita, who has alopecia and wears a hair system that requires to be replaced every six months. When Sunita is struggling to keep up with the payments, the company director offers to discount her hair system if she agrees to supply before and after photographs for their website. She feels exploited and trapped by the company, eventually managing to disconnect from them and find a more reputable salon. When we consider these experiences of hair loss through the framework of stigma, the risks of cosmetic hair treatments become increasingly visible. Goffman (1968) describes how people with visible differences can attempt to gain social acceptance “through changing physical appearance” (1968: 19). But he also highlights how this “quest” for acceptance reveals the “extremes to which the stigmatized are willing to go to”, that puts them at risk of “victimization” from fraudulent service providers (1968: 20). While I am not claiming that cosmetic treatment like Beverley’s hair system are in any way fraudulent or necessarily seek to exploit women; they do involve a dependency that can interfere with daily life comparable to the shame caused by hair loss, as I described in Chapter One. Hair systems definitely make women feel more empowered about their appearance, but their high cost undoubtedly creates challenges and could lead to increased financial risk over time. Tarlo says “there is not gain without loss when it comes to the redistribution of hair” (2016: 313), I agree, and add that there is also no empowerment without risk.

Beverley’s influence over the visibility of trichotillomania clearly involves both empowerment and risk. Techniques of concealment involve financial risk, they involve power, as well as the potential to reinforce stigma and lack of recognition for those who do not fit into models of beauty associated with white femininity. Women gain control, but also lose control at the same time. The risk of being exposed, mirrors the risk of having to reveal. The image of the bald Barbie that originally advertised Beverley’s salon in a magazine is reflected in the images of the brides with

trichotillomania who finally have their “dream hair”. Hyper-femininity permeated Beverley’s salons in the décor alone, with pink and purple colour-schemes, butterfly wallpaper, flowery cushions and framed quotes stereotyping female desire: *I love my men like I love my coffee, tall, dark and rich*. And, of course, that femininity was embodied in Beverley herself.

Beverley’s view on the value of hair for women was no secret, and she was frequently heard saying “hair is a woman’s crowning glory”. The truth is, she knows the reality of living without hair, since she has suffered from alopecia since she was a child. Her interest in and passion for helping women with trichotillomania is genuine, and she does have a deep understanding of the experiences of TTM despite not having had the condition herself. Although she attempts to relate to her clients with her shared experience of hair loss, she also distances herself in important ways. For example, as I have mentioned, one of my main concerns with the press coverage above is the inclusion of footage of women’s hair loss, like those that feature prominently in scenes from *Girls on the Pull*. In her expert interview that she gives for the documentary, Beverley is filmed talking about her reasons for starting the salon thirty years ago. She begins to open up about her life with alopecia, and the camera shows one black and white photo of a teenage Beverley wearing a headscarf. Beverley explains that she wears the hair system herself, and tells the viewer what her hair looks like underneath: “Although my hair looks like a long, thick, blonde, I think fabulous head of hair, in fact it’s a short frizzy, black, ball of fizz, with patches!” She goes on to explain the circumstances surrounding her hair loss and how difficult it has been for her, when she starts to cry, and finally says she can’t talk about it anymore. Here we see quite clearly that Beverley not only finds it incredibly painful to discuss her own experience of hair loss, but she also does not reveal her baldness to the viewers. My point is that her influence over women who attend her salon, and the offer for them to share their stories, does not take into consideration the difficulty for these women face in revealing such a private aspect of their lives. Her refusal to do the same highlights a

clear inequality in the relative visibility of female hair loss, and shows a hierarchical distancing from the women she claims to represent.

Beyond the documentary, Beverley's salon and the awareness raising she does for TTM is tied in to making a certain type of woman visible. We can see similarities between the type of hair that Beverley has chosen for herself, the image of Barbie, and the stereotypical features of white western female beauty. This image of female beauty was also obvious to me when I visited her salons, in the absence of curly hair. In Chapter One I mentioned my own vulnerability sitting across from Beverley, comparing my own image in the large mirror beside her. My curly hair made me appear messy and wild compared to her smooth, well-kept coiffure. In future visits to meet other women at her Edinburgh and Manchester studios, my curly head remained an anomaly. Stylists and clients alike only had straight hair, that ranged in colours. The hair extensions that were added to women's heads were all long and straight, despite the waves and curls that sat beneath.

The first time I met Siobhan at Beverley's salon I sat quietly as she talked quickly and excitedly to the salon staff. I watched as they carefully re-attached each of her individual hair extension bonds, making her already thick hair look even thicker. She told me she was lucky she had "so much hair" that she was mostly able to keep her bald patches hidden. Her thick long brown hair had a natural wave to it, and two staff members worked hard to brush, blow dry and smooth it out with heated straightening irons. Following her appointment, we went for a coffee together to talk about the salon in more privacy. The positivity and excitement she expressed to the staff suddenly faded as she began to tell me a more detailed story about her experiences at the salon. Siobhan explained that she didn't always like the way that staff straightened her hair. She said that in her initial consultation with the salon manager, he had commented on her thick naturally curly hair, and said: "People would *kill* to have hair like yours!" But when the time came to have her system fitted he suggested they go for a straighter style, and offered to have her natural curls chemically

straightened to match. The salon's preference for straight hair in some ways can be linked to the desire to have control over hair. In one of the email newsletters I received from Beverley's she outlined the idea of having control over "our grooming" is fairly easy:

I have a treasured cushion that was a gift to me 20 years ago it says 'HOW CAN I CONTROL MY LIFE ...WHEN I CAN'T CONTROL MY HAIR?' it always makes me smile and reminds me my life is limitless because there was a time when I felt just like that. I have been heard to say on many occasions how I love the idea that if we want more hair we have the opportunity to buy some more. It has the amazing feeling of taking back a measure of control with our grooming - what a result. Yea whoopy do dah day. It's nice that life has different options now-a-days and helps us to heal and feel more empowered (Beverley's newsletter, May 2018).

The empowerment of being able to buy the hair you desire, is obviously connected to the ability to pay for hair. The types of hair for sale are also connected to the desirable hair styles that feed the hair industry. Within this, is the obviously preference for straight Euro-American white hair over curly Black hair. The value of straight hair across the world has clear links to notions of white female beauty and highlights the political aspects of Black hair (Banks 2000). Considering what straight hair represents over curly hair, we can see how the commoditisation of hair shapes the choices women have at Beverley's and subsequently the image of trichotillomania that comes from articles that she encourages from her clients. Curly, unkempt hair is not only deemed less "beautiful" than straight hair (Young 1999: 79), or a sign of "madness" (Tarlo 2016: 146), but it is also viewed as "unbusinesslike" (Caldwell 1991: 369). Throughout history, these stereotype have shaped racist attitudes and have further reduced work opportunities for Black women based on their discrimination (Caldwell 1991). The negative connotations associated with curly hair were clearly visible to me at Beverley's, which she also reiterates herself in *Girls on the Pull* when she describes the black frizzy short hair that sits beneath her long blonde locks. The preference for straight hair is represented in their public advertising given by these women with trichotillomania, but it is also shaped by the global hair industry, which shapes the

fashion that women find at Beverley's. The hair trade continues to be one of the largest global industries, in which hair is becoming even harder to obtain; increasing its value and driving up its demand (Tarlo 2016). As one of Tarlo's interlocutors told her: "Hair is more valuable than money. You can find money anywhere, but it is only on a woman's head that you will find this!" (Tarlo 2016: 69). But Tarlo also reveals the journey that donated hair makes around the world. In her explanation of how hair is sourced and manufactured, she describes the complex gathering of hair from all over the world, followed by the intricate processes in which different types of hair are treated, dyed, curled or straightened. Across these global hair networks, Indian and Chinese hair is often re-branded as "European Hair" to meet the market's demands for blonde hair. The different fashions evident in the hair industry reinforces the fact that hair is malleable, changeable and valuable. When Beverley joked that she would "cut those curls right off me", I was reminded that the hair on my head indeed had a value.

I have summarised people's frustrations towards the lack of awareness of trichotillomania in the public culture, and their distaste of existing press coverage. From this discussion I have highlighted how power dynamics present in Beverley's salon are shaped by social beauty norms that reveal gendered and racialised expectations of hair. These norms are reproduced by the media coverage on trichotillomania that frames Beverley's hair systems as a valuable commodity and a necessary treatment for hair pulling. However, these representations are being challenged by members of the BFRB community.

### **More Than Hair**

The way that the media makes BFRBs visible can be empowering, and some of Beverley's clients who chose to reveal their experiences to the press described the process positive terms due to the awareness it raised for TTM. Yet, as I have shown, BFRB visibility in the media can be risky, and Beverley's powerful influence over these

articles reinforces an image of trichotillomania as shameful and heightens the risks associated with revealing the BFRB body. Beverley's products promote the message that female hair loss requires covering up with cosmetic treatments, and the articles frame hair as a commodity and a cure in the context of trichotillomania. The risk of BFRB visibility is therefore connected to the stigma of hair loss, and the fear of revealing it. The image of trichotillomania in the press, and the type of female beauty it represents, has clear links to a hair industry that promotes hair as the ultimate commodity and marker of female beauty. But despite what these articles suggest, not all women with trichotillomania are hoping for these treatments, or see themselves in these beauty ideals. In fact, some are quite openly resisting these norms and shaping their own identities through their hair and what it says about their journey with trichotillomania. One example of this is Lindsay, a young woman who regularly attends my Edinburgh support group. Lindsay recently made a documentary film called *More Than Hair* as part of her university coursework for a degree in journalism. In this film, Jude, from the University of Glasgow, is interviewed. She describes her frustration with media representations of trichotillomania:

Very often when you see a piece, it features photographs of bald patches and sensationalistic headlines. That is fine if the individual has chosen to do so. But remember, this is a condition where people are going about their daily lives looking quite normal... I think it's important that when one reads a piece that they see that the hair puller is not just bald and depressed, that person is also living a life, that person is also holding down jobs, holding down relationships, these aspects of trichotillomania are just as important to mention as the negatives of trichotillomania. So as I said I believe that the media awareness is great, but it would be good to have slightly more control over how it's portrayed.

Jude describes a desire to take control over how trichotillomania is portrayed, in particular she wanted people living with trichotillomania to be described in more positive terms, not just in terms of hair loss. This was the same perspective that led Lindsay to make the documentary, as she told me:

Nothing exists out there [on trichotillomania], and the stuff that does exist is *shit*. It's all about 'Oh look at what these poor people are doing to themselves' and 'Isn't this weird? Aren't they freakish?' But it's not what defines me, it's *part of me*. I'm making the film I needed to see when I was eight, and my parents found that mound of hair behind the sofa. The film that says: 'You're not a freak. You're not alone. And this is not the end of the world' [Lindsay's emphasis].

Similar accounts have been described by Bareiss (2017) who is one of the few scholars to analyse media representations of self-injury. In his paper he summarises the way self-injury has been framed in the American press as a symptom of individual distress, separate from social pressures, and one that can only be fixed by the sufferer themselves who is expected to take responsibility of their actions (2017: 291). He describes the way people living with self-injury have pushed back against this rhetoric through presenting their narratives in online forums. He notes, "Here, self-injury is not presented as occasion for blame or prescription for reintegration with a hostile environment. Rather, scars are markers of shared suffering and pride regarding strength and survival in the face of a harsh social milieu" (Bareiss 2017: 293). Lindsay is resisting the dominant narrative of trichotillomania in the public imagination, by challenging perceptions of the BFRB body. *More Than Hair* refuses to engage with the shameful revealing that *Girls on the Pull* presents, and suggests that there might be other ways of living with trichotillomania that do not emphasise the expectation of fitting into gendered beauty norms. Through making those with BFRBs visible and sharing their narratives, Lindsay is altering the visibility of the condition, and challenging the existing spectacles in the media. She echoes the frustration with media representations of hair pulling that I have described in this chapter, and subsequently makes BFRBs visible in a different way. In the next chapter, I will give example of other people who are engaging in a similar advocacy, through what I call acts of biosolidarity. As we will see, acts of biosolidarity help people to make BFRBs visible - on the body and in the public eye – and is reflective of notions of recovery that are based on accepting BFRBs rather than overcoming them.



## Conclusion

In this chapter I have highlighted comparisons between the way trichotillomania is often sensationalised in the press. These spectacles are far from new ways of entertaining the public with the image of people who are unusual or different. I have shown the power relations involved in this process, that reveal how techniques of concealment are tied up in both empowerment and risk. While public opinions of BFRBs cannot be deduced from media coverage alone, the image of trichotillomania in the public eye is certainly one indicator of how the condition is viewed and received. I not attempted to analyse the results of this media coverage on public opinion, instead, I explored the response from people living with trichotillomania to the way their behaviour is presented. I showed that people feel frustrated with these representations, and how it negatively affects the way they see themselves.

Press and television documentaries do not stand alone, and are connected to wider social and cultural views on illness, gender and hair. Using a feminist lens, I have shown how the framing of trichotillomania as a “tragic disorder” that ruins the appearances of women is intimately tied into gendered Euro-American beauty norms. This coverage both reveals and conceals certain types of people - revealing the heteronormative white female, and excluding men as well as women of colour. As I have shown, to some extent it could be argued that media accounts of female hair loss will always come down to gender and beauty norms in some respects. But from the information available to me during my fieldwork, it is clear that the public image of trichotillomania is also largely influenced by certain powerful figures within the community, and their perceptions on how the disorder should be treated. I argue that the connections between the hair industry and Beverley both influence and are influenced by the idea that women should look a certain way, and that trichotillomania is a cosmetic problem that can be fixed with a cosmetic solution. While this method clearly works for some women, the incentives offered by Beverley for women to share their stories with the press are producing a one-sided view of trichotillomania that hides the multiplicity of

people who live with it, and the variety of ways in which they cope with their hair pulling.

The hyper-visibility of Beverley and her services promotes the idea that hair is both a commodity and a cure for trichotillomania and supports the image of the white female sufferer. These assumptions about how men and women of colour experience trichotillomania in comparison to white women are problematic, not only because they reinforce isolation of these groups who are excluded from view, which has the potential to affect help-seeking of these groups, but also because they reinforce racialised and gendered differences to the experience of hair pulling that privilege the beauty of white women over others. I have touched on some of the ways that people in the BFRB community have resisted this public profile. In the next chapter I will describe an important turning point for many of the people I met, when they find out “they are not alone”, and how this information often leads towards a coming out about their BFRB, attempting to change the way that BFRBs are viewed, and how they view themselves.



## Chapter 4

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### Building a Community: Medicalisation and Biosolidarity

The Behavior Therapy Center (BTC) is situated in Silver Spring, one of Washington, DC's northern business districts. From my host family's house in Arlington, I took two metro trains and a local bus to commute there each morning for a week of fieldwork in April 2016. I had just spent a weekend in Dallas at the annual TLC conference, and my extended visit had been arranged with Dr Charles Mansueto, the director and one of the pioneering members of TLC's Scientific Advisory Board. I had met Charley (as he was commonly known) on my first visit in April 2015, introducing myself as "an anthropologist from Scotland" when I attended his introductory session on "Pulling and Picking 101". He stood at the entrance to the workshop room to welcome everyone as they arrived, alongside his friend and colleague Fred Penzel. I was excited to meet them both, as they were key authors in my pre-fieldwork literature searches, and unlike many of the researchers I met that weekend, they actually knew what anthropology was. They shook my hand and said "So you're here to study us!". Charley was especially welcoming, and over the following years showed a great interest in my work, inviting me to spend the week with him and his team at the BTC.

My first day was spent doing interviews with Charley and some of his therapists, but as the week went on, his staff began to mention to their clients that I was there, and I was able to conduct interviews with some people attending for BFRB treatment as well as a few of their parents. I was in Charley's office when his colleague Ruth knocked on the door and said she had a client who was happy to talk to me. Charley excitedly got up out of his chair and offered to give up his office for the next hour as he had a meeting to go to. He patted the leather seat and said, "Here - you can sit in the chair of power!". Once Charley left and I welcomed the woman into the room, we made ourselves comfortable on the client's sofa, sitting side-by-side.

Spatially, BTC is clinical. Each office is set up in a style that reminded me of doctor/patient paternalism; with large chairs and desks for the therapist and soft comfortable sofas for the client, reinforcing a certain degree of biomedical hegemony. Beyond the offices, corridors promote privacy with walkways of numerous closed doors. After Charley's meeting, he set me up in another office that belonged to his colleague, currently on vacation. In between interviews I found myself wondering what was going on in the closed rooms beside me, and intrigued by the lack of interaction between the different people passing through.

My next interview was with Megan, and followed an interview with her mum, Camila. As I mention in Chapter One, Megan is fifteen-years-old, and had been coming to the BTC for just over two years. She told me that despite being against the idea of therapy, she was happy to come to BTC because it "specialised in trichotillomania". Mid-way through our conversation, when Megan had finished telling me about her low self-esteem, and her techniques of hiding her hair loss, I asked her if she had ever met anyone else who had trichotillomania.

- Megan: Um... Nah, unfortunately.
- Bridget: Well, I do... I've had it since I was about nine or ten... maybe you'd like to ask me some questions?
- Megan: How were you able to fight those voices or fight those emotions that made you, like, crumble?
- Bridget: Well, everyone's different, but I'd be lying if I said that those voices weren't still there. But, the voices of the people that love me are there too and they're louder.
- Megan: [Softly] Yeah, they are [...] I've never met someone else with it, and it feels good to know that I have. And I have to remember that I'm not alone, there's people like you and me, and there are so many others. It makes me relieved that there's other people. My friends just don't get it. Even talking to you, I feel like I can open up, and it feels really good to be able to do that.

The environment of BTC is structured in a way that the individuals within it are concealed within its walls, and in this example, Megan loses out on the opportunity to meet other teenagers like her, despite many of them passing through the same

building each week. My realisation during the BTC visit, was that many clinical spaces are set up in a way that focuses on individualised therapy, and often overlooks the relational aspects of care.

In this Chapter I show that while a medical label can make other people with that label visible, diagnosis and medical care do not go hand-in-hand. Through examples of people “finding out the name” of their BFRB, I describe the meaningful ways that the BFRB community becomes visible through the shared labels. But diagnosis also reinforces a sense of isolation as it reminds people that there is no “cure” for their condition; a conflict that highlights an irony of medicalisation. It is ironic in the sense that although the biosocial group develops around these medical labels, medical labels do not lead to medical care. Instead, I show how people use the biosocial group towards self-care and collective self-care. By describing the meaningful relationships that emerge within the biosocial group, I also highlight the challenges of building and sustaining this community. Within these limits to biosociality as a concept, we see how acts of “biosolidarity” can account for the ways that people in the BFRB community advocate for increased recognition and representation in the public imagination.

### **“You are not alone”**

I was eighteen-years-old when I realised my hair pulling had a name, ten years after it began. Jude started pulling age six, and was twenty-three when she self-diagnosed. She was my first official “trich friend” when we met during my master’s degree in 2012. Shirley found out the name when she was in her fifties - after almost forty years pulling - during which time not a single person knew about her secret. In the same internet search that told her the name, Shirley found my call for research participants on the Trichotillomania Support UK website. I was her first “trich friend” when we met several weeks later, and the first person she had opened up to about her hair pulling. The moment of finding out “you are not alone” is important for people with BFRBs due to the isolation and hiding that many people experience in their daily lives. The discovery

of a name comes with the realisation that there might be other people in the world “just like you”, and opens the door to a potential support network that was previously non-existent. After this moment, a new way of understanding their BFRB as an identity emerges through the language of the DSM, which makes both the label and the labelled visible in the process of diagnosis. Naming creates the ability for people with BFRBs to become visible to one another from online searches, and offers the chance to find and build a biosocial community.

The internet has offered people new ways of finding and creating communities, and was an important tool for my interlocutors in discovering they were not alone. During my master’s research in 2012, I scanned Facebook support groups for people describing this moment:

I googled ‘eyelash growth’ to find out how long I would have to wait, then I saw the word Trichotillomania and wikipediad it and I remember feeling my heart racing and I suddenly felt really hot and I felt tinglings going down my spine and through my fingers... I realised I wasn’t abnormal and that I wasn’t alone (Lara, Facebook).

I had actually never thought to Google ‘hair pulling disorder’ because I thought I was the only one to do this. But low and behold, here we are! And I’m so thankful everyday I’m not alone and I have support and understanding here (Sophie, Facebook).

I will never forget the day when I discovered that this evil inside me has a name. I decided to randomly type ‘pulling out eyelashes’ into Google and suddenly, hit after hit after hit came up, with the same word, ‘trichotillomania’. As I opened each link, the tears rolled down my face. I was crying with such joy, that this THING I had done to myself for seventeen years, had a name. I was not alone, as I had thought all those years, living in shame. I finally felt somewhat free (Hope, Facebook).

These narratives reveal the legitimacy gained from discovering “the name”, and the way that psychiatric labels can create meaning, offering people a way to make sense of an otherwise inexplicable behaviour. An important revelation in these experiences was connected to the possibility of relatedness; to discover “you are not alone” and that there are other people “just like me” was a life-changing event. In addition, these

examples show the unexpected-ness of finding other people, and that to some extent the discovery of finding the name happened by chance. Like we saw in Chapter Three, the somewhat random process of stumbling upon a newspaper or magazine article came as a real surprise, but so too is the moment of typing in “hair pulling” to a search engine and it being translated into a medical label. The importance of a label is paramount in this process, and is aided by the use of media and “new media” such as the internet.

Gray (2009) has followed the use of new media in relation to LGBT experiences of community, and writes: “new media serve not primarily as ‘opportunities for the formation of new communities... spanning vast distances’ but as opportunities to create and consolidate networks much closer to home that are otherwise absent from mass-media representations” (Gross 2007, cited in Gray 2009: 12). In similar ways, my interlocutors were able to form relationships with people with a shared experience, despite many of them living in different parts of the world. Here we see how the internet makes people visible in an imaginary sense; an imagined possibility of meeting others. Importantly, finding one another in online groups becomes easier once the label itself is discovered, and therefore to some degree the visibility of a group is dependent on the existence of a medical label. Online spaces allow people to negotiate and control their visibility, by becoming revealed to each other in online groups, while at the same time remaining concealed in everyday life. By connecting online people are increasingly likely to connect physically, and to find one another locally; through the formation of support groups and group meet-ups. But as I will show, finding a community and forming a community are different, and in the context of BFRBs in the UK, there were no support groups until Dhaya and I started them. Therefore, biosociality is dependent on the effort of people to create the community, and to sustain it.



## Meaningful Medicalisation

The transition from isolation to relatedness that comes with “finding out the name”, can certainly be seen in the narratives above. The sudden onset of BFRBs, the unique multi-sensory urges they embody, combined with the lack of public discourse on them, has led to deep isolation and stigma within everyday experiences. We have seen the negative self-perception that BFRBs instil in people, who hide their behaviours in creative and arduous ways; and how this negative self-esteem is often reinforced by family members. I have described at length the ways that all of this adds to the feeling of being a “freak”, which was mentioned regularly by men and women with BFRBs. Discovering a name for these often indescribable experiences offers people the opportunity to find an explanation for what they do. In this sense, I argue that gaining a BFRB diagnosis allows people to move from abnormal to normal through their new label, as they are no longer an individual with a “weird” habit, they are now part of a group who have a recognised health condition. There is a contradiction here that speaks to Martin’s (2009) example of mental illness diagnosis. In *Bipolar Expeditions* she describes how the diagnosis of “manic depressive” moves her from rational to irrational, “Since the category manic depression denotes an irrational condition I appear to be trapped in a circular process that robs me of the ability to be a subject at all: once I occupy the subject position of the irrational, my actions will always be interpreted as irrational, no matter how much I protest” (2009: 128). In the example of manic depression, Martin shows how the connotations of the label are connected to representations of the illness in the American media, corporate advertising, as well as history of mania more generally. However, as I have argued, the presence of BFRBs in the public imagination is far less than other mental illnesses, which appears to have influenced reactions to the discovery of this label. The lack of public awareness means that people are less likely to come into contact with the “name”, and more likely to think they are the “only one in the world”. As such, finding out there are other people just like you, gives people a reason for their otherwise “abnormal” behaviour.

In the introduction to this thesis I gave an overview of the way that BFRBs are classifications that are continually moving and changing, largely due to the advocacy that comes from TLC and the BFRB community. Although evidence of BFRBs has existed throughout history, some of my interlocutors described the importance of when it was officially “named” in the DSM. Jude said: “I grew up in the seventies, when it wasn’t even a *thing*”. Researchers working with TLC over the years have aided the movement and improvement of BFRB classifications, successfully managing to have skin picking included in the DSM V as per their suggestion (Stein et al. 2010), as well as suggesting that BFRB become recognised in the ICD 11 (Grant & Stein 2014), which happened in 2018 (World Health Organization 2018). BFRBs are a recent example of how a patient community has emerged hand in hand with the labels, with TLC’s founder, Christina Pearson forming the organisation in 1993, just a few years after trichotillomania was entered in the DSM III-R (APA 1987). Arguably the increase of people with skin picking attending the conference in 2016 is likely a result of TLC’s change in name to include BFRBs, and the recent inclusion of skin picking in the DSM V (APA 2013). This confirms what Hacking has described as “looping effects”; whereby certain types of people become visible alongside the development of new labels (Hacking 1995, 1998, 2007).

Hacking argues that the process of viewing new “kinds of people” can alter our perceptions of those people as individuals (1995: 354). This aspect of diagnosis in particular has been explored widely within medical sociology through the concept of “biographical disruption” (Bury 1982). Recent authors have argued that biographical disruption is not always a negative experience, and that psychiatric labels in particular can have a positive impact on the sense of self (O’Connor et al. 2018). As we saw in Chapter One, the sense of being “different” and “unusual” reinforces the need to keep BFRBs hidden; and therefore the existence of a label can alleviate some of these feelings. Although psychiatric labels may change the way others perceive those who are labelled, in the case of BFRBs, having the label of a “mental disorder” does not increase the fear of stigma, instead it can make people feel less ashamed:

I only discovered that I had Trich about a month ago and I was pretty terrified, but so relieved to discover it was what I called a 'real thing' rather than something unique that made me disgusting (Olivia, Facebook).

I only went 3 months undiagnosed because my mother noticed and a week later read an article about it in her Advanced Clinical Nursing journal...Those several months not knowing I was normal were the scariest, loneliest, and most anxious of my life (Trisha, Facebook).

[T]he pulling (starting at age 13) kept me lonely for a very long time. There was no one in my life who understood this thing. I was fifty-years-old when I found that this actually had a name. It didn't change the facts, but I knew I was not alone anymore (Marianne, Facebook).

Diagnosis brings authenticity to BFRB experiences, and these women express their relief in knowing their otherwise "unique" or "disgusting" behaviour was "real". Trisha says she now knew she was "normal" as she had an explanation for what she did. Before diagnosis was loneliness, fear and anxiety. So while diagnosis can often have a positive impact on professional help-seeking, for my British informants it rarely led to positive encounters with doctors. Instead, people were often left feeling disappointed with their doctor's lack of knowledge on the condition. Finding out the name also brings an element of fear and anxiety, as Olivia mentions, and as Marianne says, it still "didn't change the facts". In many ways the psychiatric label offers people legitimacy, but it also opens the door to the unknown, and for many people this involved the disappointment of realising their medical label did not come with a medical treatment:

I found out Trich had a name from the Daily Mail, when I was about 15. I was relieved to know I wasn't alone, but it didn't really help me in my day-to-day life; I was still bullied at school, I still hated the way I looked and felt, I still couldn't convince my parents, teachers or doctor to take me seriously (Ruby, Facebook).

When I found out, that it has a name, this moment truly hit me hard. But the moment, when I found out, that there is no guaranteed cure for it - that moment made me... crushed...broken... (Cecile, Facebook).

The expectations that accompany psychiatric labels can be seen here, alongside the hope that there might be support options or better understanding. Cecile feels “broken” by the realisation that she cannot be cured, but for Ruby her expectations also bring her the hope that having a new label will offer her a way to communicate with the people around her that she seeks support from. Here we begin to see the emphasis on community, and finding support from other people who share the diagnostic label:

It was only when I went to university and began to connect with other people on message boards (and of course, meeting a few real-life sufferers) that I started to open up and talk about my trich, thereby helping me to see patterns, triggers and ways of coping. It’s the interactive nature of the board that is so useful, and the fact that this board in particular is so open and tolerant. I feel I can say anything here (Ruby, Facebook).

The looping effects that Hacking describes not only shapes how outsiders perceive newly labelled people, but influences how people view themselves as a new “kinds of people” - from whom valuable support can be found. The social aspect of looping effects is under-developed in Hacking’s work, and by concepts like “biographical disruption” (Bury 1982) which tend to focus on the individual experience of diagnosis. As this chapter continues, I argue that it is the process of finding others and forming biosocial connections that makes diagnosis meaningful. These examples show the power of diagnosis for people living with BFRBs, as well as the value of relatedness found within support networks. However, the case of BFRBs also reveals an irony to medicalisation; although diagnosis brings people together, it also triggers a necessity to find and shape a biosocial community due to the lack of medical care. In the next section I will expand on this irony to medicalisation; illustrating the disappointment that can come from doctor-patient relationships.

## **“Have you tried sitting on your hands?”**

Diagnosis has long been considered an essential component to treatment outcomes in clinical medical practice, although views on its emphasis are changing (Croft et al. 2015). In my discussions with the researchers and clinicians associated with TLC, the idea that diagnosis leads to treatment was represented through the DSM, and was expressed through their lobbying for more accurate labels to represent these behaviours. Clinicians were concerned with the classification of hair pulling and skin picking as “self-harm” or “OCD” as it was believed that wrongful diagnosis could lead to inadequate treatment options (Stein et al. 2010). The change in category in the DSM V (APA 2013) to “obsessive-compulsive and related disorders” was considered positive as it was a more accurate representation than the previous category of “impulse-control disorder not elsewhere classified”. However, the change has also led to frustrations as the new category means that clinicians are more likely to prescribe antidepressants for patients with BFRBs, which have been shown to make symptoms worse in many cases. Of course, the reality is that for many diseases and chronic illnesses, diagnosis does not lead to treatment; however, it does trigger expectations of care. In the case of BFRBs, finding out there is a name gave many people, like Cecile above, the hope that there might be a “cure”. And while being “cured” may be the hope for some, the medical care received for BFRBs following a diagnosis often falls far from this expectation, with very low awareness or support being displayed by professionals. This section will describe the disappointment that people experienced with medical professionals, which further strengthens the value of biosocial connections in the BFRB community.

Throughout my fieldwork in the UK, I was continually struck by the number of oblivious and unhelpful comments given by healthcare professionals to the people I interviewed. Many people told me about the negative responses they received when seeking medical help for their hair pulling or skin picking. The advice given by some doctors like: “Have you tried sitting on your hands?” or “Have you tried stopping?”

showed a lack of awareness around BFRBs and their intensity. People also hoped for reassurance from professionals, and were left feeling a continued sense of self-disgust after visiting the doctor, as Maud told me during my master's interviews: "I was embarrassed because of their [the doctor's] attitude, they didn't say so but the way they looked at me like I was some sort of weirdo". I was frequently told about the how doctors appeared "perplexed", with some proceeding to do a Google search as they admitted they had never heard of the behaviours before. Frustration was also common for people who managed to work their way through the NHS system, sustaining the long waiting lists for cognitive behavioural therapy. The high hope of getting tailored therapy was soon diminished as therapists were rarely trained in BFRBs, and often appeared to know little about these conditions. Although CBT can of course still be useful and offer beneficial tools without being tailored to individual needs in this way, the disappointment that came from these interactions led most people to give up hope in medical care. For those visiting the doctor after many years without a diagnosis, finally admitting to a professional that they pulled out their hair or picked their skin was an embarrassing thing to do.

Revealing their BFRB often left people feeling vulnerable and so baffled or unhelpful comments had lasting effects on people and reinforced feelings of isolation and shame. Importantly, for people with compulsive skin picking, there were an increasing number of stigmatising reactions from general practitioners due to the high prevalence of skin picking among drug users. There were other common diagnostic misconceptions about BFRBs, for example that hair pulling and skin picking was assumed to be a form of self-harm. Not only was this assumption frequently made by healthcare professionals, but people themselves were unsure how to relate to this classification, as we saw in Michael's example when he was confused as to whether or not his behaviour was self-harmful. For the majority of my interlocutors, having hair pulling or skin picking labelled as self-harm often made them feel an extra level of stigmatisation.

According to accounts of self-injury, we can see where the self-harm label might bring unwarranted stigmatisation, not only from lay people but from health professionals themselves. Chandler (2016) has described the intense stigma that people who practice self-injury often receive from emergency hospital staff. She explains how stereotypes surrounding self-injury and attention-seeking are widespread among health professionals, as well as misunderstandings of the role of pain. As one woman told her about a time she visited A&E to have her open wounds stapled together, upon asking if she was going to get any anaesthetic she was told: “Nah, you’re a self-harmer - you did this to yourself... so I don’t really care” (Chandler 2016: 126). Chandler argues that these stereotypes held by health professionals reflect a lack of understanding of the complex embodied experiences of self-injury in relation to pain, and have a detrimental effect on help-seeking behaviour among people who self-injure. Like self-injury, BFRBs involve embodied experiences that are often more complex and nuanced than simple medical classifications account for. People who live with self-injury and BFRBs arguably face additional stigma due to the visible effects on their bodies, putting them at risk of judgement from health professionals.

As I have described in Chapter One, the BFRB body is rarely revealed due to fear of the stigma that it may bring. The effort involved in techniques of concealment highlight the depth of this secrecy in everyday life. Chapter Two showed how revealing the BFRB body to family members often brought further stigma, and Chapter Three placed this in the context of public culture. The role of diagnosis then, can bring hope of legitimacy rather than embarrassment. But when doctors reinforce feelings of shame; it pushes people further into isolation. We can see the different ways that diagnosis is understood and practiced for people living with BFRBs, and how expectations of care are shaped by labels given to illness. But this care is dependent on the knowledge of doctors, as well as the level of empathy and compassion that plays out in these interactions. Chandler argues that the brutality of responses that her informants received from A&E staff has the potential to directly influence future help-seeking behaviour, and in the same way, negative responses from the doctor in response to

BFRBs made many of my interlocutors avoid seeking further help. It is through these failures from medical professionals that people with BFRBs go on to develop self-care practices which are strengthened by their inclusion in a biosocial community.

### **Becoming Biosocial**

In Chapter One, I outlined some of the ways that people with BFRBs manage on a daily basis. The continuous application of make-up, wigs and hair systems, act as both techniques of concealment as well as practices of looking after the self. They simultaneously allow people to feel “better” about their appearance, while creating short-term barriers to trigger areas. Due to the loneliness and lack of support, people with BFRBs learn to take care of themselves through various coping mechanisms. Cheryl wore plasters on her fingertips every day, to lower the sensitivity in her hands that normally triggered urges; Lewis found exercising regularly helped him to re-direct some of the nervous energy that often preceded a skin picking spree; Cara noticed that by cutting out sugar from her diet she experienced urges much less; Denise kept a pot of Play-Doh by her desk to give her hands some alternative sensory stimulation while at the office. Many of these techniques are suggestions made by behavioural and habit-reversal therapists during the therapeutic process, but were often solutions that people had come up with on their own due to a lack of professional care. Following diagnosis, and the realisation that professional care is limited, many people began to search for others who shared their experiences, creating a care network that offered something that medical care did not: expert advice and genuine empathy.

When I first met Lou, she was a client at Beverley’s salon in London and had been wearing one of their human hair wigs for over a year. On our first meeting she told me how much she liked visiting the salon, and that the staff were all lovely and made her feel very comfortable. But she also said that going there made her feel anxious, and seeing herself in the mirror meant facing her trichotillomania in ways that she found very difficult. Lou and I spent time getting to know each other and met several times



when I was visiting London. As time went by, she also decided to come to the first London support group meeting that Dhaya and I had organised together in January 2016. Lou was one of fifteen people, and when the time came for her to share with the group, she got extremely upset and was comforted affectionately by the others, who offered tissues to dry her tears and hugged her. She seemed embarrassed after the meeting and apologised for getting so upset, though we all reassured her that it was a safe space for her to share her emotions in any way she needed to. The following month, I was happy to see Lou return to the support group and completely amazed to see her without her wig. Her head was buzzed short, and she looked confident and happy with her new style. She said she was still getting used to her new image, but felt much more like herself. I never saw Lou wear her wig again.

BFRB week came around again, and Dhaya and I prepared to spread awareness on the streets of London with our BFRB Awareness Stall. We had shared updates of our events with the support group members, some of whom came along to join us. Towards the end of the week, Lou emailed me to say she had decided to write an article to help raise awareness (Figure 8). It included a picture of her smiling with her shaved head. In it she wrote:

The thing that has helped me the most has been getting to know other people with BFRBs. I now go to a monthly support group, and it's amazing being able to talk about the frustrations and challenges with people who know exactly what you are going through. I can talk freely about my trich now. If someone asks why I have a shaved head, I'll just tell them it's because I pull my hair out and this helps me to manage it. I never could have imagined being so open when I was younger, and overcoming the shame associated with this behaviour has been liberating.



Figure 8: Lou: "Conditions like trichotillomania aren't talked about enough"

For Lou, getting rid of the wig and embracing her new appearance with her shaved head was an important process in her recovery journey. It shows that there are different approaches to living with trichotillomania, and different ways of coping. Beverley's salon definitely offered Lou, as well as many women I met, a safe and comfortable space. Hair systems also helped women to feel confident and re-gain an element of their self-esteem. What is important about Lou's experience, is that despite the relationship she had with the salon staff, who knew about trichotillomania and made her feel comfortable, there was something about attending the support group that changed her perception of herself. In turn, she went from feeling deeply ashamed when faced with her trichotillomania in the salon mirror, to being able to come out publically and share her story.

Lou made an important transition, comparable to several others I met during this research process. While she had gone through the diagnosis moment of finding a name for her hair pulling earlier in life, subsequent disappointment with doctors, and finding help from Beverley's salon, it was only when she met others with BFRBs that her own self-care journey became a relational experience. Through the support group,

a collective self-care<sup>15</sup> is created, where people are able to care for themselves in new ways through the support of one another. Collective self-care was practiced in a variety of ways, through hearing and sharing personal stories, recommending sensitive hairdressers and therapists, or exchanging tips on what make-up works best for eyelash cover-up, and what different fidgets bring satisfying sensations. I argue that collective self-care is an important aspect of biosociality, and highlights the limits of the current biomedical model. However, this is not to suggest that individualised biomedical care is “bad” and community-based care is “better”, and in fact, biosociality can be a fraught and challenging form of community.

### **Beyond Biosociality**

Rabinow’s (1996) concept of biosociality has been used by many anthropologists to show the ways that people form communities around a shared biological experience. But the biological nature of biosociality has been challenged. In the context of HIV/AIDS in Tanzania, Marsland (2012) has argued that the social relationships hold more value in forming biosocial connections than the biological marker of disease, as she notes that people often do not need to disclose their HIV status in order to form meaningful connections. For this reason, Marsland proposes the term (bio)sociality to reduce the emphasis given to the biological attributes of biosocial connections. Marsland says “biosociality does not look inward to the body, but outward to human relationships. Whilst people might share a common biological predicament... this was not the basis for their shared experience” (2012: 474). Like Marsland, I agree that BFRB biosociality is not dependent on coming out publically, and as I have shown, efforts to remain secret extend throughout the life course. However, the biological or embodied attributes of BFRBs are important factors in forming biosocial connections, due to the lack of understanding of these embodied elements from families and health care professionals. As I have argued, the role of the internet makes this process possible,

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<sup>15</sup> In Chapter Five, I will expand the notion of collective self-care, when I describe the way that the BFRB community is considered a “family”.

and allows people to become biosocial while remaining secret; thus biosociality involves both being revealed and concealed to different people, at the same time. Yet, the process through which people find and shape a biosocial community is largely overlooked, as are the challenges and frustrations that this process involves.

When Michael and I met in October 2016, he told me how he found it difficult to make sense of his own behaviours until discovering there was a name for them. As I mentioned in Chapter One, Michael experiences the urge to bite and pull the hairs from his arms with his teeth. He has always found this combination of biting, pulling and picking confusing, and deeply shameful, being unable to explain it, and feeling intensely embarrassed when people saw him doing it. He was, in a way, out of place and anomalous, and when he went looking for Facebook groups online and only found groups full of women pulling out their head hair he said, “that’s not me”. Just before contacting me about my research, Michael discovered the term “body-focused repetitive behaviour”. The new label of “BFRB” helped him to feel accepted, he said: “It was like a family of things, and that included me. That’s something I can be a part of, and that feels good”. Michael’s example acts as a reminder that diagnostic labels have the ability to include and exclude different people, and that exclusion from a classification can create a sense of not-belonging that can cause significant damage to one’s sense of self. It also shows the direct relationships between labelling and sociality, and how biosocial groups can exclude as well as include people depending on their unique labels.

Thus, biosociality also involves exclusion, and Bridges (2011) has highlighted that not all groups have the opportunities to coalesce in the way that Rabinow suggests. In her example of marginalised Black women at New York City’s Alpha hospital, biosociality brings with it the label of “high-risk” which has major implications for treatment and health outcomes of pregnancy women and their children (Bridges 2011: 171). In Chapter Three, I argued that there are certain groups of people who feel excluded from the BFRB community largely on the basis of gender and racial identity. These

“inclusion” categories are exacerbated by the media in their portrayal of “the white female TTM sufferer”. This gendering and racialisation is also reinforced in narratives of biomedicine, as psychiatric research describes statistics of women compared to men, and higher numbers among white communities. As I have argued, the secrecy of BFRBs has influenced demographic data and thus research outcomes. By examining Hacking’s idea of looping effects, we can see that the hyper-visibility of certain “kinds of people” in the BFRB community, limits the opportunity for “other kinds of people” to become part of the biosocial group. Clearly, biosociality is not straightforward and there are often barriers and challenges to forming a biosocial group. In my own journey towards building the British BFRB community, I encountered some biosocial challenges of my own.

In October 2015 I set up the first BFRB support group in Edinburgh, closely followed in January by the London support group which was started by Dhaya, with my assistance. During this time, attendance to these groups fluctuated, in Edinburgh, we welcomed between 1-5 people each month; and though we started off well in London with 15, in other months only 5 or 6 attended. Dhaya and I were not overly concerned by the low numbers, and we accepted that even if one person turned up it would be worth it. As 2016 progressed, I continued with my fieldwork, splitting my time between Edinburgh, London and the North of England where some of my key informants lived. I was spending quite a bit of time in the Manchester area conducting interviews with individuals, as well as visiting Beverley’s salon in the city for sporadic appointments. During some of these interviews it emerged that I had started support groups in London and Edinburgh, and some of my interviewees said they would be keen to attend a support group, but these locations were too far for them to travel. After some consideration, I decided to start another support group in Manchester. Not having much luck through various contacts at several venues, I ended up having to pay for a room myself, which alongside the rail travel was becoming costly; but I carried on for several months. The Manchester group started in May and attracted 4 people, 3 in

June, 1 person in July and in August no one attended. Feeling defeated, I decided to cancel the group after just a few months.

In the work of running the support groups, Dhaya and I have encountered numerous challenges. We both struggled with the time and effort these groups required alongside family life, and due to the size of the London group which needed two facilitators, Dhaya and I rarely had a month off. I continued to travel to London each month after my fieldwork had finished and I had since become pregnant, until we found someone to take over from me to assist Dhaya. Despite our strong friendship, the pressure of maintaining this biosocial space was proving difficult for both of us, and put a strain on our relationship as well as our energies. For those who attended the group, many were happy and continued to come regularly. Others came once and never returned, and we never knew why. Some new attendees complained that there wasn't enough structure or focus in the groups on "treatments", and wanted a more twelve-step approach. Heather once told me that she disagreed that people with skin picking were allowed to join the group, as she felt she unable to relate to experiences of skin picking.

Meeting the expectations for a group of this kind, without therapeutic training, also affected our own abilities to feel part of these groups, and Dhaya said regularly that she did not feel the group could "benefit" her, as she was too concerned about other peoples' needs. I also found running the groups stressful, and on one occasion especially I felt completely out of my depth. Having recently been to the TLC conference where they screened the *Trichster* documentary, I decided to buy the film and show it to my Edinburgh group. Joy and Shirley were both attending that month, both participants in my research but neither having met one another before. Having seen the film about five times by then, I knew it well and I thought it was a very accurate account of the BFRB community, showing the positive aspects of biosociality in particular. But after the film, the room was silent. I raised the lights and sheepishly asked what people thought. Everyone was very quiet, and I began to feel nervous, as

if I had made a terrible mistake. The colour had drained from Joy's face, and I realised she looked as if she would burst into tears. Shirley began quite honestly, and said she found it shocking. She couldn't believe that people could be "that bad" that they had to wear wigs and cover their hair. She admitted she was happy she wasn't that bad, but she felt very uncomfortable watching it. Sitting across from her, Joy said it had made her feel triggered, and she found herself wanting to pull her hair the whole time she watched it. As she spoke the tears began to flow. She apologised as she continued crying and said she didn't know why she was crying. Immediately after, I phoned Dhaya on the way home and tried to figure out what I had done wrong. Dhaya was supportive and reassured me that there was no way I could have anticipated those reactions. After that meeting, neither Joy nor Shirley returned to the support group, although I went on to meet them a few more times before my fieldwork ended.

These examples are only a reflection of the support group space, which in itself is a very particular type of biosocial environment, although it is one that has rarely been the focus of conflicts. These reflections show that biosociality is not always harmonious, and it certainly does not allow for unquestionable inclusivity for all. My experiences also act as a reminder that different forms of biosociality require maintenance, governance, and that these structures can create social tensions and practical and financial pressures. Biosociality is fragile, fraught, and importantly it is dependent on people working together through shared labour for its ongoing sustainability. People who work to create biosocial groups also have important social backgrounds, with certain emotional needs which can shape the birth, life and death of biosociality. In recognising the limits of biosociality, we can see the importance of social relations to those who seek to form biosocial groups, despite the challenges. The value placed on coming together through shared experiences is highlighted in the attempts people make to strengthen biosociality. For Dhaya and I, having the benefit of the biosocial group was one thing, but the decision to start a group was another; that decision to *do something* more for the community, is what I refer to as an act of biosolidarity. These types of actions were done by different people in numerous ways.

Acts of biosolidarity highlight the importance of biosociality, while also addressing some of its limits.

### The Circle of Biosolidarity

So far I have argued that diagnosis offers legitimacy to experiences of hair pulling and skin picking, and offers new opportunities to find effective self-care strategies through collective self-care in support networks. For many of my interlocutors, this process remains somewhat private, and did not involve a public “coming out” like Lou’s above. However, for several of my key informants, the process of finding out the name and becoming part of a community inspired them to *do something* productive through various forms of advocacy work. In this section I will show how this productivity can be understood as a form of biosolidarity, where the biosocial community formed through shared BFRB experiences influences actions towards changing the way BFRBs are represented and understood. As I will further show, it is through this biosolidarity that the BFRB community becomes visible; and attempts to shape the way their BFRB identities are seen in the public sphere shapes the way people perceive themselves. This visibility subsequently creates more opportunities to connect, and for the community itself to grow and prosper. In his account of the Deaf community, Friedner (2010) argues that deafness can be productive. This productivity is linked specifically to sociality, as he writes: “The medical diagnosis of deafness ultimately serves as a ticket of entry into the Deaf community” (Friedner 2010: 339). Friedner suggests that the Foucauldian model of biopower does not go far enough to account for these productive forms of community, and argues that power is not unidirectional, but it can operate from below and is influential in the creation of subjects. Foucault proposes two meaning of the word “subject”: subject to someone else by control” and “tied to his own identity by a conscious or self-knowledge” (Foucault 1983: 212). Friedner argues that through the development of a Deaf identity, people become able to act on themselves through techniques of the self, governing the self through self-care. This interpretation of Foucault’s self-care model shows that self-care can involve



bottom-up forms of power, and that entering a new biosocial group can offer productive forms of self-governance that reclaim the biopower otherwise imposed by medicalisation. In this section, I show how members of the BFRB community use self-care practices in productive ways to create a sense of biosolidarity with one another. Through various forms of advocacy, they have challenged the poor representation that exists for their community, and have subsequently made BFRBs visible in new ways, helping to strengthen collective self-care within the BFRB community.

Skin picking was almost non-existent in the media coverage, and in comparison to trichotillomania, skin picking has suffered a slow and challenging journey to gain recognition. In relation to diagnosis, it only recently gained an official DSM label in 2013, where it is labelled “excoriation disorder”, although the majority of people still prefer its more widely used name - dermatillomania or “derma”. Despite efforts by TLC, skin picking continues to have a lower profile in the United States in comparison to hair pulling. Its recognition in the British context is worse still, but in the UK there is one woman who has worked to increase the visibility of skin picking in extraordinary ways.

Liz Atkin is London-based artist who combines her creativity with efforts to share her skin picking story with people all over the world. In the spaces where Liz is usually affected by skin picking temptations (on the London underground to work for example), she uses charcoal to scribble attractive and unique drawings on free newspapers, which she hands to strangers along with an explanation of why she is doing it. She calls this her one minute "Compulsive Charcoal" series, and it is a beautifully simple and powerful metaphor for compulsive skin picking: fast, all-consuming, messy, visible. She uses her art to literally push her skin picking out of her body and on to paper, raising the profile of the condition and changing the way it is viewed by the public. Every day Liz gives away about 60 drawings, and very often she meets someone else who struggles with skin picking, many of whom have never met another person who has it, some not even knowing the behaviour has a medical name.

In my conversations with Liz, she told me, “drawing saved my life”, and she talked openly about her history with anxiety and depression which make skin picking worse. For Liz, this act of biosolidarity is strongly influenced by self-care. She draws first and foremost to keep her skin picking at bay, but the conversations that arise from this public art display provide opportunities to raise awareness at the same time. Liz is expressing biosolidarity with the BFRB community, and extending the opportunities for the strangers she meets to become part of that biosocial as they “discover the name” like others have done. Biosolidarity connects people through biosociality, but also acts as a form of caring for herself, and reinforcing the care of the community as a whole.

During my fieldwork, Liz invited me to an event where she had been asked to do a live drawing. It was early October 2016. I waited for her at Dalston Junction station, which was busy on a Friday night at nine o’clock. I watched as the crowds of people ascended the escalator, emerging suddenly from underground, eventually seeing Liz among them. She was smiling and colourful, with bright red lipstick, multi-coloured rainbow high heels and a roll of paper on her back the size of a small tree trunk. She rushed towards me excitedly and we hugged affectionately. On our way to the venue, we popped in to a convenience store to buy baby wipes, an essential handbag item for her when she draws with charcoal almost constantly. She told me that because she had forgotten her baby wipes she was unable to draw on the train, as she wouldn’t have been able to clean her filthy hands afterwards. She held up her little finger to show me the damage she had done to the skin all around the nail which had been peeled away, showing how easily she slips back into her picking routine without the tools she needs to keep it maintained.

At the event that evening, Liz had been asked to do a large-scale charcoal drawing at the launch of a fashion magazine that features some of her artwork. We arrived at the venue ahead of the launch to get set-up. Heading down the dark staircase into a basement, I felt as if we were on the set of *Doctor Who*, walking along a long white

corridor which looked like a tunnel made of cubes, decorated with twigs and sticks. In the rooms leading off the corridor there were photographs from the magazine hanging from gold wire, more obscure props and colours, and music playing in the background that sounded like noises from the seventies kids show *The Clangers*. Liz and I were shown where to get set up, and I helped her to tape the huge sheet of paper to the wall. The editor of the magazine gave Liz a long white doctor's coat to wear, which she accepted politely while turning to me raising her eyebrows and smirking. She got set up and started to draw as the guests began to arrive, working surprisingly quickly as rough sketches of mountains suddenly appeared on the white sheet. I watched her for a while as she travelled up and down the wall of paper, her whole body moving and taking over the

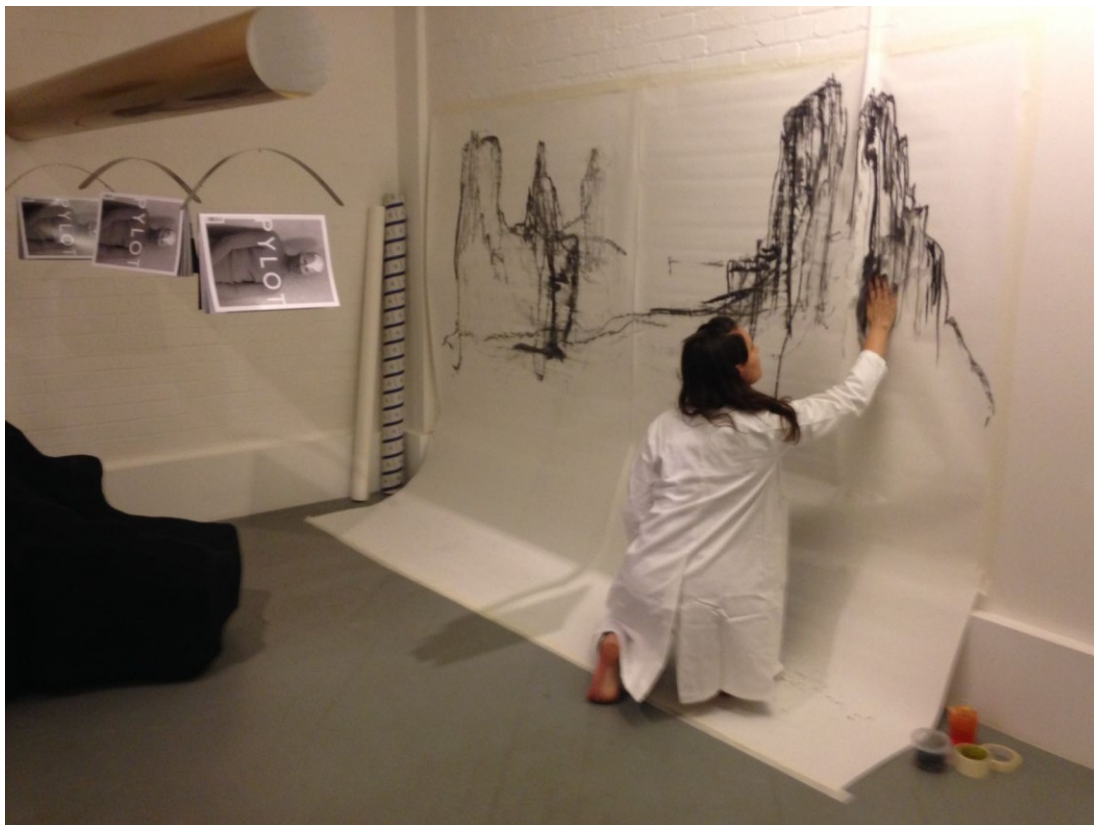


Figure 9: "Pouring Mountains" by Liz Atkin

drawing (Figure 9). Her hands were instantly filthy, covered in black charcoal dust, and so was the white coat. I started to ask her questions while she drew. "How does it

feel?" I asked. She said: "I feel the energy of the illness, it's fast". For Liz, the movement of her body, and the sensations associated with drawing replicate that of skin picking, and so she is able to replace her BFRB with her art. She described the similarities between the two: the speed in which she moves; the feeling of the charcoal on her skin; the pincer-like positioning of her fingers as she holds the charcoal which would be the same positioning of her fingers for picking; the trance-like zone she enters which helps to make her feel calm; and the production of something satisfying at the end. Liz told me that the charcoal is perfect substance to work with too, as it prevents her from touching her face or skin at the same time as drawing, or else she would be covered in black dust. After she completed the wall-drawing, Liz decided to do some compulsive charcoal drawings for the guests who were milling around the room, enjoying the complimentary gin cocktails (Figure 10).



Figure 10: "Compulsive Charcoal" by Liz Atkin

I watched as she approached people, asking if she could draw them a picture. Her advocacy was in full swing as she began to tell people why she draws and more about the "illness" that she keeps at bay. When she was finished each one, she gave them to people as small gifts. They are beautiful drawings, both messy and intricate sketches of mountains surrounded by dark clouds. I asked her, is it ever hard to part with these drawings? She said: "I learn not to be precious with them because I see the value in *this*" - she holds up her charcoal covered hands, showing

me that keeping her hands busy and away from her skin is more valuable to her than the art she produces. The value in Liz's charcoal drawings goes beyond the personal self-care that she relies on, and also beyond the cherished artwork that she gives to grateful strangers for free. Through this embodied self-care, she maintains control of her disorder while she draws, but at the same time she is making skin picking visible in new ways to the public. She is shaping the way skin picking is represented in public culture and influencing the growing advocacy for the BFRB community.

I have argued above that finding the biosocial group of BFRBs sufferers can trigger acts of biosolidarity, seen for example in Lou's desire to write an article after feeling the benefit of the support group, and Liz's artwork. Both of these acts had an impact on others when they were shared, and in this way acts of biosolidarity can trigger further biosociality. Meeting other people with BFRBs, and the actions that many people choose to pursue to raise the awareness of BFRBs, has the reproductive potential to create connections with others. Thus, these interactions suggest that biosociality and biosolidarity produce each other. This "circle of biosolidarity" was most evident to me during the TLC conference in Dallas of April 2016. Liz Atkin had been invited by TLC to give the keynote speech on the first evening of the conference weekend. She began:

I've come a long way to be standing in a room of strangers, who have the same understanding of the disorder I've lived with all my life... this quote is really important to me so I'm just gonna' read it out: 'There is a vitality, a life-force, an energy, a quickening that is translated through you into action. And because there is only one of you in all time, this expression is unique. If you block it, it will never exist through any other medium and it will be lost. The world will not have it. It is not your business to determine how good it is or how valuable or how it compares with other expressions. It is your business to keep it yours clearly and directly and to keep the channel open'.

Liz's talk was a powerful overview of how skin picking had dominated her life, and how she managed to turn it around with her art and advocacy. The audience whooped and cheered loudly in response, and got to their feet, filling the room with loud applause. Liz was visibly moved, and clasped her hands to her face, wiping away her tears. When

she left the stage, a spontaneous line formed towards Liz, with people queuing patiently to talk to her. She stood for over half an hour talking to each person, hugging them affectionately, many of them in tears as they thanked her for sharing her experience. In the queue that evening was Lauren, a first-time attendee to the conference, and a long-term sufferer of skin picking. I had the opportunity to talk with Lauren as the weekend progressed, and it was clear that this experience was going to be life-changing for her.

A few months later, I saw on social media that Lauren had decided to start her own non-profit organisation dedicated to skin picking. She called it “The Picking Me Foundation” and it is the first organisation in the world dedicated to skin picking. Since then, Lauren has travelled across the US to attend mental health conferences, designed care packages for people with skin picking, and worked with clinicians towards improving support for the disorder. The connection between Liz and Lauren is just one example of how biosociality can produce acts of biosolidarity and vice versa. We can clearly see how biosociality and biosolidarity work together in circularity: people meet one another as part of a biosocial group, and some are inspired to form acts of biosolidarity. These acts of biosolidarity reach new people who become part of the biosocial group, and so the circle continues.

This circle of biosolidarity is the very foundation that TLC is built on, with its founder Christina Pearson, arguably the mother of the TLC family. Describing her to me as “the woman who changed the world”, a leading BFRB clinician told me about the early years of TLC, and how Christina “gave birth” to this organisation. In a recent article, Christina’s early TLC journey was documented:

The news that there was a name – trichotillomania – “rocked my world,” she says.

After decades of feeling shame and isolation, she began to feel hope: there were others out there living with the same condition. Pearson started a support group. A Seattle news network invited Pearson to appear on air, where she spoke about her life and provided a number for a trichotillomania hotline that she planned to operate herself.

She returned home to over 600 messages.

“People were crying and sobbing and begging for help,” says Pearson, who spent a week calling each person back. “It was the best therapy I ever had, because I heard my life coming out of other people’s mouths.”

One night in bed she had what she calls a peak experience, or spiritual vision. Pearson decided to walk away from her business and devote her life to improving public awareness of trichotillomania. “I was scared shitless. Me: I’m a drug addict, I’m a small-business person, I’m in sobriety, I have an eighth grade education, and I’m going to get out there and change the world and some weird pathological disorder?” says Pearson. “I just was terrified.”

But then she adds: “When we receive that kind of inspiration, what I’ll say is this: We are called all the time. Rarely do we choose to respond.”

(Talpos 2018).

Christina went on to collaborate with the small number of clinicians and researchers that were interested in trichotillomania at that time, and twenty-five years later they formed the Scientific Advisory Board that has grown in reputation along with the organisation. The “calling” she describes can be seen as an act of biosolidarity, through which the circle has continued to grow and reproduce. Christina’s calling echoes the quote from Liz earlier in this chapter; of the life-force that is translated through people into action, creating a channel that can circulate throughout the BFRB community, and shows how biosolidarity is a political tool that has the power to bring people together through a shared cause.

## Conclusion

This chapter began with the moment of diagnosis, and showed the power that a psychiatric label can have on individuals with BFRBs. We have seen the ways that naming changes the way people view themselves, often feeling “normal” compared to the time they spent before being diagnosed. I have highlighted the value attributed to BFRB labels, alongside the tensions that arise when labels change. Furthermore, I have critiqued the role of diagnosis in relation to care, showing how expectations of

treatment following diagnosis often fall short. The disappointment and failure that people often encounter with health professionals causes many of them to take care into their own hands. These self-care practices can be seen as a form of resistance to medical care in the sense that people are finding alternative ways to cope.

However, through diagnosis, individuals' self-care strategies can become collective self-care practices, and with the support of a BFRB network, self-care becomes relational. From diagnosis comes biosociality, which can lead to productive self-governance, by which hegemonic biopower can shift into grassroots control from below. I have argued that this productive power can fuel acts of biosolidarity. As I have shown, biosolidarity is the productive way in which people advocate for their disorder and others with it. Often spurred on by the intimacy of connecting with people who share experiences, it is the process through which individuals advocate for their communities, and make them visible, with the aim of reducing stigma of their disorder. Through this increased visibility, comes the potential to further connect with those who are yet to find the name; and so biosolidarity reproduces biosociality.

In the BFRB community, biosociality is driven by a sense of isolation, making connections with fellow sufferers increasingly meaningful. In coming together, people can value the support of others in higher regard to medical or kinship support, as this often lacks empathy and embodied understanding. Collective self-care allows people to care for themselves, through the support of one another. It is this turning point that has led to the alternative forms of recovery that I have witnessed in the BFRB community. In the following chapter, I explore biosociality as a form of recovery, and by focussing on the TLC family, I will show how compassion, love and relatedness are influential in the process of caring for the self.





## Chapter 5

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### Love and Recovery in the TLC Family

Robyn stretched out her long hands to show me the remnants of scarring on her fingers. I could barely see a thing, and she pointed out that she had trying to take better care of her hands after years of picking the skin around her fingernails until they bled. As we walked slowly along the Southbank river, she told me about her struggles with self-care in the past. She said, “I think if you tell yourself that you’re not really worth looking after, then you just don’t”.

For many people with BFRBs, the challenges of practicing self-care were linked to low self-esteem. In this chapter, I discuss the process of overcoming this low self-esteem, and describe how people attempt to practice self-compassion through self-care strategies often involving material objects as “technologies of care”. I show how certain technologies of care involve transforming triggering objects into tools that help to alter the perception of self. I argue that both self-esteem and self-care practices have to be learned and practiced; further, they are deeply relational and shaped by the BFRB community. I argue that the TLC family encourages “circles of care” (Lesshafft 2016), where self-compassion is made possible through the love of the community. By examining the TLC family, I will unpack the role of love within this biosocial community, showing how the TLC family is based on ideal forms of kinship as “loving” and “caring”. But the TLC family is like any other, and therefore inherently involves conflict, responsibility and financial obligations. Here we will see the way that recovery is made possible through relatedness, but opinions surrounding recovery are conflicted – and creates ongoing friction within the TLC family.

#### Self-Esteem and Self-Care

Milcho stood confidently on the stage and addressed the room, the sequined accessory on her bare head sparkled in the light. As the keynote speaker for the 2018

TLC conference, she matter-of-factly told the few hundred attendees that they have the power to take control of their behaviour by changing the way they see themselves. She shared her own story about how she managed to overcome her anxiety and hair pulling by shaving her head, and learning to love herself. As a film-maker and producer, she had prepared a video on what she called the “selfcrush project”. The short film



*Figure 11: Milcho's  
#selfcrush mirror*

triggered laughter from the audience as it featured men and women (who do not have BFRBs) talking to themselves in a mirror. Each person in the video was asked to say what they thought about themselves, and tell themselves “I love you”. By the end of the video most of them were shouting “I love you” emphatically and laughing at the awkwardness of being in front of the mirror and the camera. After the film, Milcho directed our attention to the gifts on the tables in front of us: little plastic packets each containing a pocket-sized heart-

shaped mirror. On the mirror the word #selfcrush was printed alongside the TLC logo. Milcho set us the same task, and requested that after the conference weekend, when we had left the security of the BFRB community, we should continue to tell ourselves “I love you” daily. She wanted us to begin there, and the room broke out into soft mutterings of people speaking to themselves. After Milcho’s speech, I put the tiny mirror in my bag, and when I returned home to Edinburgh I stored it in a drawer, ignoring my own selfcrush task.

Milcho recognised that for many people, even those without a BFRB, telling yourself in the mirror “I love you” is awkward and difficult. It became clear to me that for people with BFRBs, mirrors in general were challenging, and that people did not find the image of themselves easy to look at. As I have outlined in Chapter One, fear of stigma and revealing the BFRB body influences people’s perceptions of self. These experiences of stigma have influenced their negative sense of self, which many described as “low self-esteem”. While the relationship between stigma and self-

esteem has been complicated more recently in the context of mental illness (Camp et al. 2002), explanations of “self-esteem” in general are often overlooked in psychology, and are simplified by global measurements of self-esteem that do little to account for the variety of lived experiences that shape the way people see themselves.

Within anthropology, Edmonds is one of the few scholars to examine self-esteem in depth, showing how self-esteem becomes the basis for legitimising plastic surgery in Brazil (2010). Edmonds suggests that self-esteem has become a global notion, although as a concept it still appears incomprehensible from a cross-cultural perspective. Contrary to “talking therapy”, where the mind has the ability to treat the body, in the context of plastic surgery Edmonds argues that improving the body can heal the mind. Self-esteem has come to be known as the illness for which plastic surgery is the cure. As one surgeon put it, “What is the difference between a psychoanalyst and a plastic surgeon? The psychoanalyst knows everything but changes nothing. The plastic surgeon knows nothing but changes everything” (Edmonds 2010: 76). In this ethnography, self-care is also considered an aspect of improving the mind and the body, and Edmonds explains how *vaidade* or “vanity” was connected to self-care through what he called “beauty work”. He notes that vanity “often has a neutral meaning of ‘self-care’ that means to preserve or enhance femininity” (Edmonds 2010: 197), thus to neglect ones’ appearance was to neglect care of the self. Edmonds’ notion of self-esteem helps to understand the relationship between the body and the self for people with BFRBs.

While people did mention having “low self-esteem” as a result of their behaviour, in the context of BFRBs it was often discussed as a result of the visible changes to the body. As Diane told me, “Hair pulling has affected my confidence because the visual signs of it make me feel ugly.” It was sometimes described as being “like a chicken and the egg situation” - a cycle with no clear beginning or end - where the effects of hair pulling and skin picking create low self-esteem, and then low self-esteem triggers further pulling and picking. In contrast however, self-love and self-compassion were

used interchangeably to describe an emotional self-perception, that could be achieved not necessarily by changing physical appearance, or *enhancing* femininity, but by accepting and embracing the way they look. As I showed in Chapter Three, many women that I have described were actively resisting these gendered beauty ideals. In contrast with Edmond's work in Brazil, for people with BFRBs improved self-esteem is not dependent on altering the body, but in altering the *perception* of the body. In some ways, this follows a psychoanalytical understanding of the talking-therapies can influence self-esteem. However, as I have shown in Chapter Four, people with BFRBs rarely follow through with biomedical treatments. Therefore, self-esteem influences self-care in alternative and often unexpected ways.

In Milcho's selfcrush project described above, self-esteem is a product of self-compassion, and self-compassion can be learned. However, self-compassion is better learned with other people; it is an ongoing process, that needs to be practiced regularly in order to be successful. Thus, self-esteem and self-care are interlinked; mutually dependent on one another. People with BFRBs who have low self-esteem find it difficult to care for themselves, but through the care of others they can improve self-esteem and practice self-compassion through self-care practices. This process can be understood through Lesshaft's notion of "circles of care" (2016). In her work on healing within the Candomblé Afro-Brazilian religion, Lesshaft argues that caring for others is simultaneously caring for oneself. Lesshaft writes, "When caring for others becomes an act of caring for oneself, it loses its altruistic or self-sacrificial character. At the same time, self-care also loses its self-indulgent, ego-centred attributes, and both melt into a circular, relational practice of generating strength, well-being" (2016: 5). In the context of BFRBs, self-care is also relational, although not all attributes of the self are lost. For people with BFRBs who have low opinions of themselves, arguably a more ego-centric altruistic approach is required in order to hold a higher perception of the self, and to warrant self-care. As Robyn said earlier, "I think if you tell yourself that you're not really worth looking after, then you just don't". Caring for others not only stimulates self-care, but self-care is dependent on, and strengthened by, the care

of others. It is also influenced by self-esteem. Improving self-esteem can allow people to take better care of themselves, and through learning compassion for the self, people can gain a sense of recovery through acceptance.

In Chapter Two I described the way that like kinship, care has a dark side. Although the negative aspects of care are rarely acknowledged by anthropologists, some have described the ways that self-care can be perceived as negative or harmful. Schüll's (2006) work on gambling addictions demonstrates how experiences of self-care and self-harm are hard to differentiate. She challenges the notion that self-care as a practice always leads to positive self-transformation, and argues that self-care for gambling addicts also contains an element of harm. The idea of caring for the self that Foucault (1997) describes is firmly based in relations of power and knowledge. It is a process of transformation through which the "self" can achieve certain states: "[Technologies of self-care] permit individuals to effect by their own means, or with the help of others, a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality" (Foucault 1997: 225). Foucault acknowledges the relational aspects of self-care, but does not mention how self-perception might hinder self-care. While his description of self-care suggests transformations which lead to positive states (happiness, purity, wisdom), "care" does not always imply positive self-transformation. This relationship between care and harm shows that notions of care and recovery are not always obviously positive. In the case of compulsive gambling, Schüll (2006) argues that the simultaneous technologies of care and harm are instrumental in achieving balance in the overall experience of "health". She suggests that rather than *transformation* of the self, people rather aspire to a state of *maintenance*. Schüll's example shows that care and harm complicates our ideas of recovery as positive, or "cure", but is more complex.

On self-care, Frank (1998) had suggested that we should not be so concerned with what “caring for the self” actually *means*, but rather we examine the practices that this process involves: in this case the relationships that are present in the circles of care. In what I have described above, the notion of recovery as acceptance that is promoted by many at the TLC conferences, may be seen to provide justification for people to continue hair pulling and skin picking, which are often perceived as “harmful”. But, it could be argued that hair pulling and skin picking behaviours actually offer people elements of self-care (in pleasure and satisfaction), although they undoubtedly also bring emotional and social harm. Lavis (2015) has made a similar argument for eating disorders, where she says that while not-eating is considered distressing by outsiders, for people living with anorexia, not eating acts as a way of regaining control that numbs negative emotions and allows people to “cope” in everyday life (2015: 97). Here we can see parallels between Lavis’ work and Chandler’s (2016) account of self-injury; where seemingly “harmful behaviours” can relieve tension and act as methods of coping with painful emotions. As this thesis has shown, much of the harm that comes from BFRBs is the anxiety surrounding the stigma of how the BFRB body looks, as well as the embarrassment of urges and feeling out of control. Moving towards acceptance allows people to alleviate some of these feelings of shame, altering the way they see themselves through the support of each other.

### **From Trigger to Tool: Technologies of Care**

Milcho’s selfcrush project is as an example of how a triggering object can be turned into a technology of care. In Chapter One, I described the ways that mirrors are fraught for people with BFRBs; they are triggers, and they hold a view of the self that people are often deeply uncomfortable with. And yet, Milcho suggested that the mirror can become a tool if people are willing to practice the selfcrush. The use of the mirror shows how the idea of selfcrush is linked to notions of self-care and how triggering objects can become tools for recovery by helping people to view and care for themselves in new ways. Selfcrush is about challenging yourself to love yourself

despite low self-esteem. Milcho's own story, and her message to the conference, is about acceptance, and taking control of your own recovery through self-compassion.

The idea triggering objects becoming tools for recovery, builds on scholarly perceptions of the relationship between technology and care. Mol's (2008) work examines the role of technologies in understandings of care for diabetes in the Netherlands. Focussing on clinical settings, she shows the way that people use technologies in daily life to manage chronic experiences of diabetes. Challenging the notions that "good care" is in opposition to technology, she says that care, "is not opposed to, but includes, technology. And the technology that I will come to talk about is not transparent and predictable". Mol argues that we ought to pay attention to what technologies are *supposed* to do, but also to what they *happen* to do, even if this goes beyond our expectation. She describes the transformative ability of technologies:

Technologies are unruly. Once introduced into a world where they interfere in unexpected ways with lots of other erratic entities and configurations, they change much more than they were intended to, and are ultimately transformed themselves as well... Keep a close eye on your tools, adapt them to your needs, or adapt yourself to theirs. Technologies do not subject themselves to what we wish them to do, but interfere with who we are (Mol 2008: 50).

Mol does not describe these technologies as "technologies of care", but I expand her work to show how objects can become caring when people use them in unexpected ways, like Mol mentions. The use of a mirror to view the self is, of course, to be expected, but the use of these tools to view the self *positively*, is unexpected in the context of people living with BFRBs who generally consider these objects to be triggering, or to hold an image of the self that they find distressing. Moving these objects from triggers to tools allows them to become technologies of care; transforming the way that people see themselves. In what follows, I argue that these technologies of care also have a with relationship to biosolidarity; whereby the positive image of the self, can become an act of biosolidarity - positively changing the perception of the community.



We can see the role of visibility in Milcho's experience; as she learns to accept the way she views herself with a shaved head. Others expressed similar movement towards accepting the way their BFRB had changed their appearance, and I regularly heard comments like: "there is so much more to me than just my hair"; "hair should not be a validation of a person". TLC conferences helped people to gain a level of confidence in self-acceptance, and challenged normative beauty ideals that reinforced stigma around the conditions as I argued in Chapter Three. People talked openly about how their skin picking scars "told a story" and their hair loss made them "who they are". Acceptance allowed people to reclaim their identity, which often involved a revealing the BFRB body; removing wigs and make-up. Milcho's selfcrush project can therefore be understood as an act of biosolidarity, that involves the use of technologies of care. Liz and Dhaya were also using technologies of care in their acts of biosolidarity; material objects that helped them to view themselves in a new way, connecting self-compassion and self-care, while at the same time raising awareness and creating alternative representations of how BFRBS are seen.

Liz told the story of the moment she decided to turn her suffering with skin picking into something productive. During her master's degree in dance, and she was given the task of filming herself in motion. Daunted by this prospect, Liz knew what the camera would eventually show, well aware of how her body "moved" when she was left alone. As she began filming, very quickly she became distracted from the dance, and forgetting the camera, she retreated into the "zone" of skin picking. The process of watching the footage, presented Liz with the reality of how out of control her skin picking was. She decided to make skin picking the focus of her master's dissertation, leading to an exhibition of how the disorder affected her body. Liz eventually formed a career through her creative representations of skin picking. Alongside the "compulsive charcoal" series I described in Chapter Four, Liz's art collection includes a series of photographs that capture her skin picking. She told me that through this work the camera became the mirror, and by turning the camera on herself she was able to capture the way skin picking was seen and experienced on her body. When discussing

these photographs, she said that the project was about making parts of the body visible that were previously hidden, and in particular to represent the embodied sensations of skin picking (Figures 12-15).



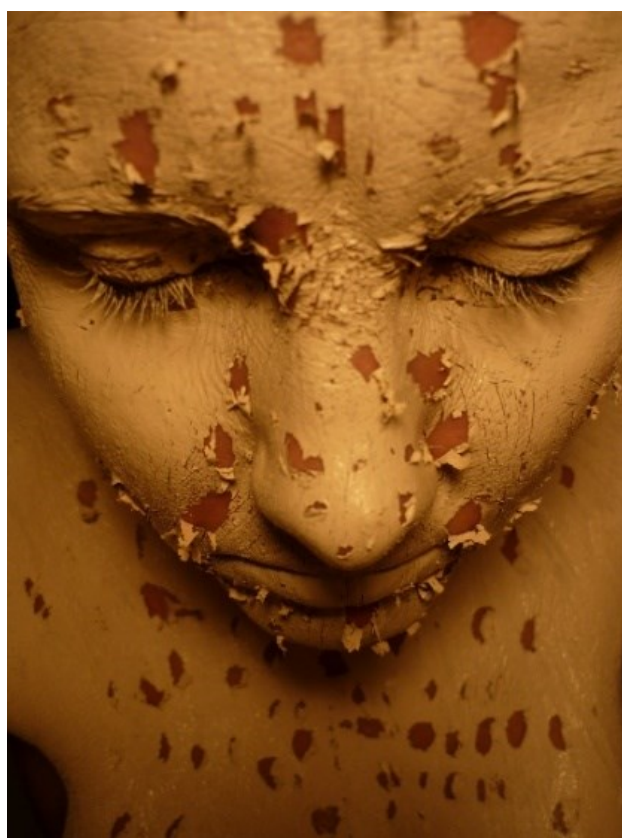
*Figure 12: "Resilience" by Liz Atkin, 2016*



*Figure 13: "They Come Not As Single Sparrows" by Liz Atkin, 2011*



*Figure 14: "Blue" by Liz Atkin, 2013*



*Figure 15: "Acrylic: Los Angeles Residency" by Liz Atkin, 2008*

In the same way that mirrors move from being triggers to tools, Liz was able to turn the shameful image of her body with skin picking, into an empowering act of biosolidarity, using technologies of care. The camera, along with the photographs it produces, becomes a technology of care by producing images that resist the shame of BFRBs, and changes her perception of her body marked with skin picking. The act of making these photographs, not only captures this positive image of her body, but the process itself makes her *feel better*, thus it becomes self-care. Like “compulsive charcoal”, Liz’s photographs show that some acts of biosolidarity seek to represent the way skin picking *feels* by taking on these features itself: messy, fast, disturbing, constant. Here the “bio” in biosolidarity, speaks not only to the social connections that biosociality involves – sharing embodied experiences with others – but shows that acts of biosolidarity can be communicated beyond narratives, can be creative and expressive representations of how BFRBs feel.

Dhaya also managed to make her acts of biosolidarity embodied, through engaging in the selfcrush project. For her, the use of “selfies” in social media posts was a way that she could present a positive image of herself, in an attempt to gain increased self-compassion. Following Milcho’s talk at the conference, Dhaya regularly posted selfies tagging #selfcrush. Having known her for some time by then, I was aware of her low self-esteem, which was particularly connected to her appearance. To me, the sudden influx of selfies then signified a change, and she started posting close-up pictures of her face, adding the #selfcrush hashtag. It was evident that this task was far from easy, when one day the caption read: “#selfcrush even on the hard days”. Dhaya used selfies to view herself in a new way, and by re-framing the image of herself in a positive way and sharing it with others. The camera becomes a technology of care, and through embracing the image of herself in the photograph, she attempts to gain more self-compassion.

Self-compassion involves accepting the self the way it is, including the flaws. It is linked to acceptance as a form of recovery because it supports the idea that you can live well

with a chronic disorder that changes bodily appearance. However, the journey towards self-compassion does not always require that the BFRB body be *revealed*. As Dhaya said in one of the TLC workshops, “Just put your hair-piece on and go and live your life”. In what I have argued above, self-care is linked to self-esteem, and so arguably cosmetic treatments also have the ability to offer people the opportunity to gain a positive view of the self, and ultimately improves self-esteem and confidence.

Returning to the salon, we are reminded of the way that techniques of concealment, too, can become technologies of care, like the Intralace System for example. On my first visit to meet Beverley, she wanted to show me proof of the transformations of her “TTM girls”. She whisked through photographs on her iPad to show me the “before” and “after” examples of the Intralace System. Describing these women by name, she told me what they looked like before, how they behaved when they first came in: timid, quiet, embarrassed; and how transformed they were with their new hair: confident, happy. When I returned to meet Beverley in her office for the second time in October 2015, she gave me more examples of these transformative stories of women. She showed more pictures and said, “Just look at her smile”. It was clear to me that many women who attended Beverley’s salon had experienced visible transformations from which they felt a positive change, and during my observations at the salon in Edinburgh, I began to see these transformations for myself.

The first time I attended the Edinburgh studio with Joy, she seemed nervous in the first few minutes while the stylist Anna was checking how many of her hair extensions needed to be replaced. Joy told me that she always dreaded this “moment of truth” as it told her how “bad” she had been in between visits. Anna reminded her that at least she was pulling at the extensions rather than her own hair. She looked at us both through the mirror, holding up the limp brunette stands and said “*these* I can replace!” After the initial inspection, Joy began to relax in her swivelling armchair and the women proceeded to catch up on each other’s news; the topics switched from work, to holidays, ‘boys’ and weddings. Anna took her time to replace all 55 of Joy’s hair

extensions, matching them carefully to the colour of her natural hair. Joy was then transferred to Lucy, who styled Joy's hair into subtle curls. By the end of the appointment, the initial nerves and guilt had faded, and Joy was smiling widely, thanking all the staff. After she had paid at the front desk and confirmed her next appointment in exactly six weeks' time, we left the building together. I asked her, "How do you feel?" As we walked she bounced cheerfully along the street and said: "I feel so confident and *normal!*"

In these transformations, the hair system acts as both a technique of concealment and a technology of care; simultaneously covering hair loss which improves self-esteem, which in turn has the potential to lead to self-care practices. And yet some women I spoke to at Beverley's still experienced a great deal of negative feelings associated with their new hair; guilt each time they went for appointments (and had to admit they had been pulling in between visits); anxiety around the cost of up-keep; and the ongoing stress of trying to become "pull-free". Technologies of care, therefore, also involve risk and elements of harm. Their use is dependent on an ongoing process of negotiation and maintenance.

The technologies of care I have described, involve sociality, reinforcing the idea that self-care is relational and self-esteem is influenced by others. Liz's drawings and Dhaya's selfies became productive and meaningful when they were shared with others; when handed out on the train or circulated online through social media. In the context of the salon, techniques of concealment were also enhanced as technologies of care through their social meaning. From my observations it seemed that these positive transformations were largely influenced by the relationship women build with Beverley herself. When I met Beverley for the third time in October 2015, she told me a story about a client that I found quite remarkable. During her first consultation, the young woman had admitted to Beverley that she had attempted suicide seven years earlier. When we met, this woman had recently sent Beverley an intimate email explaining the impact she had had on her life. Beverley chose to read out the email to

me. It said, “Seven years ago I died, but you helped to bring me back to life... If I could ever grow back a full head of hair, I’d pull it all out again the next day just to have the chance to meet you again”.

In this example, we see a contrast to many of the women I met at Beverley’s where the relationship formed at the salon appeared to be more important than having a full head of hair. For most of the women I met, visiting the salon made them feel “normal” and “comfortable”, but the “care” that they valued in this space was the hair system rather than the social relations. This was perhaps due to the fact that Beverley rarely visited the Edinburgh salon. In my conversation with Sandra, she reiterated the bond that she shared with Beverley and how it had helped her to overcome her hair pulling:

I am absolutely convinced that had I not met Beverley I would not have changed. I’m not sure that I would have got to the point that I am now without her, not at all. You know she’s quite a spiritual person, she’s a *healer*... but she is, it’s funny. The whole place is just built on love; her love of hair, her love of wanting to help, her love of wanting to do good [Sandra’s emphasis].

Sandra emphasises that love was important in her relationship with Beverley, and key to her experiences of being cared for at Beverley’s salon. In Chapter Three, we saw that Beverley’s “love of hair” was tied to certain notions of female beauty, which influences her perspective on hair as both a commodity and a cure. Her “love of wanting to help” and “do good” allows us to further question the notion of care as a moral act, with expectations of love, affection and positive transformation. But, as I have argued, care inherently involves elements of harm, particularly care within kinship relations. So, while Beverley’s salon certainly involved technologies of care, which like other technologies of care, had the ability to improve self-esteem; the salon setting did not involve the circles of care that I have described above. Again we are reminded of the value of relatedness that is central to biosociality. In the next section I will unpack the importance of biosociality to notions of recovery, and further develop the relationship between love and care in the TLC family.

## From Hiding to Healing: Biosociality as Recovery

In my examples so far, I have argued in that people are able to care for themselves in new ways through the support they give one another. I have shown, that people often use self-care practices in place of medical treatments. In the space of the TLC conference, the support of the BFRB community provides a compassionate and caring environment that can lead to self-transformation and reduced shame. The intimacy that connects people with BFRBs is often described as a family, and the process of attending a TLC conference, and entering into this family, often sparks a transformation in people that begins their road to recovery.

Throughout my observations at TLC conferences, and at UK support groups, I was surprised by the way that these opportunities to come together became effective in peoples' recovery journeys. Looking back to Lou's example in Chapter Four, she said that the London support group had been the main thing that had helped her throughout her life with trichotillomania. On a different scale, attending a TLC conference for the first time was often quite transformative for people. I witnessed many of these transformations during my first conference in 2015, but I also experienced this for myself. After meeting Jack on the balcony that year, we entered the ballroom and looked for a table to join. We said hello to the others at the table, and I noticed the young girl beside me, who wore a colourful bandana and was slumped low, staring at the table. I introduced myself to her mother, Penny, who explained that it was their first time at the conference. I waved the blue ribbon on my lanyard that said "First Time Attendee". Her daughter, Tiffany, looked up at me for a moment and as I smiled at her, I noticed her lack of eyelashes and eyebrows. She quickly returned to look at the table. Meeting Tiffany resonated with me, and seeing her bare, pale face without eyebrows, ashamed to look me in the eye, reminded me of my own struggles with trichotillomania at her age. The next morning, Penny and Tiffany came to find me at the breakfast table. Penny chatted positively about the very busy first day they had had, the workshops they had attended and the friendships



Tiffany had already formed with children her age. Tiffany was smiling confidently that morning, and was in a hurry to rush off to meet her new friends. Throughout the weekend, we continued to bump into each other and I got brief updates about their activities. Tiff was even considering going swimming with the other children, which Penny implied was a big step for her. On the final day of the conference, after the closing speeches, I went looking for Penny and Tiffany to say goodbye. The room was filled with people hugging, and crying, sad to leave their friends behind for another year. Most realised that they were returning to daily life without the supportive community that understands them and accepts them for who they are. Tiffany came running up to me, hugged me tightly, and asked if she could have a picture taken with me.



*Figure 16: Tiffany and I at the TLC conference 2015*



*Figure 17: Tiffany and I at the TLC conference 2018*

Penny took our photo, and I told her more details about my research, and asked if we could keep in touch. Not long after the 2015 conference, I got a short email from Tiffany with some updates. In it she said: “When I got back from DC I was pulling a bit more. I think it is because I’m not around my TLC family anymore. It feels good to be home I just wish there was someone closer to me who has trick [sic]”.

I saw Tiffany and Penny again at the next TLC conference in Dallas, April 2016. This time Tiffany’s dad, Mark, also came along. Penny and Mark echoed Tiffany’s wish of having people around them who could support her and them. Penny said,

When you leave [the conference] there’s a good chance most people leaving don’t know other people around them that do it, you know a lot of the other disorders that parents struggle with with kids, you have your community right there with you, because there are a core group of kids that have autism or Down’s syndrome. But you have that network right there with you most of the time, and so the isolation is a big thing, you know I don’t know anyone, there was no one else.

Mandy also expressed these sentiments in relation to her daughter Frankie. On leaving the conference she said: “The problem is when we get home, because *this*

[conference] is heaven” [Mandy’s emphasis]. I heard regular stories from people who experienced a period of total BFRB cessation following the conference, like Jude who attends every year, and every year she manages to stop pulling her eyelashes for several weeks when she returns to Scotland. But these few weeks of being pull-free were always followed by a relapse. While the conference offers something effective for people, I would argue that the efficacy is found in the intimate bonds of an idealised relatedness, where the idea of “family” is centred around unconditional love and belonging.

Jennifer Raikes, TLC’s Executive Director, took the stage after the 2018 conference fundraising dinner. She said: “They say that having dinner together is important for a family’s health, and it is true for our TLC family... but we need this love and connection more than once a year”. The family metaphor could be heard consistently at all of the TLC conferences I attended, although it seemed most prevalent during my visit in 2018. Almost all of the speakers mentioned it in some way, emphasising the attributes that make this community a family. Jennifer introduced the next speaker, Aneela Kumar, founder of the company HabitAware, and designer of the Keen Bracelet, an electronic technological bracelet that gently alerts people to their pulling and picking behaviour. Aneela’s speech described how she came to find the TLC family and the way she had transitioned from “hiding to healing” because of them. She said, “With TLC as my companion I have made peace with my hair pulling”. She went on to thank TLC for their role in her recovery journey saying, “Thank you for welcoming me into your family, after two decades of not knowing where I belong”. This sense of belonging, and of coming out of hiding is evident from my earlier examples in Chapter Four, when I explained the importance of meeting other people with BFRBs. Many people described this as similar to meeting long-lost relatives, and described the sudden bond that was felt between those meeting for the first time. (Solomon 2012). As I mentioned in the previous chapter, the moment people find out the name, and discover other BFRB sufferers can be a life-changing event. This sense of isolation that precedes this moment helped to strengthen the bond between people when they met

for the first time, which many people described as “It’s like we’ve known each other forever”. One woman said: “It’s because you’ve lived your life with this deepest darkest secret about yourself, and then you meet someone else who has it, and you can finally be yourself”. But attending a TLC conference was frequently described in kinship terms: “It’s comforting, like coming home to family”.

Linking back to Chapter Two, we saw how experiences of family life between mothers and daughters cause people to reflect on their ideals of family care. Like Dhaya who said, “growing up I think I would have liked to hear ‘we love you no matter what you look like’”. In the TLC family, unconditional love and belonging is offered, despite the stigma that physical BFRB bodies bring. As my discussion has shown so far, this is a major element in the idea of acceptance as recovery.

In April 2018, I attended the annual TLC conference for BFRBs for the third time. Always finding it difficult to decide which workshop to attend from the vast selection of coinciding events throughout the weekend, for the first session I opted for “What is Recovery?” I arrived early and helped Pam, the workshop facilitator - whom I knew from previous TLC conferences - arrange a small circle of chairs in the large room. She said she wasn’t expecting a big group, so we tried to keep the space intimate and inviting. Slowly the room began to fill, and we had to shuffle around to add more chairs to the growing circle. Eventually we sat in a circle of around sixty people, spread out so that people had to raise their voices to share their stories. The question of “what is recovery” began to be answered by the group, and it quickly became clear that BFRBs have a recovery spectrum, with many people feeling as though acceptance was the goal rather than becoming “pull-free” or “pick-free”. One young woman said, “For me, recovery means I don’t beat myself up or feel ashamed [when I pull my hair]”, another said “I think recovery is surrounding myself with people who know about my hair but love me anyway”.

Kinship is in itself a powerful form of biosociality, so in many ways it is unsurprising that people refer to the community as a “family”. When I asked the Maxwell family about this “family metaphor”, Tiffany’s parents, Penny and Mark said quite clearly, “it is *not just* a metaphor”. For them, calling it a metaphor reduced the value and meaning in these relationships. So instead I began asking, what makes TLC a family? The biosocial connection is an important factor in the TLC family, due to the shared embodied experiences of hair pullers and skin pickers. Following on from the fundraising dinner at the 2018 conference, the Chair of TLC’s Board of Directors (and father to thirty-year-old Katie, a long-term hair puller), began his speech: “TLC is a family because we all feel so much love, don’t we?” What I have described so far in relation to biosociality is the intimate connections people feel towards one another from belonging to a group, often strengthened due to the long-term isolation that came before. In Chapter Four I described these biosocial connections, when I witnessed in online groups, as well as support groups I was attending in Edinburgh and London. But the environment of a TLC conference was different in ways that I consider important to notions of kinship. Firstly, the intensity of the conference weekend with people spending several days or more together usually within the same hotel. The conference itself runs over three days, but since many attendees have to travel from across the United States (and a few from beyond) people often arrived earlier and stayed for a few days after to maximise their time together or visit local tourist attractions. This experience of co-habiting or proximal closeness adds to the intimacy of the conference, and influences the sadness of leaving the conference and returning home to communities where similar support networks do not exist. Eighteen-year-old Zara highlighted the closeness of the TLC family in an Instagram post for BFRB Awareness week 2018:

It’s nearly the end of #BFRBweek but the week wouldn’t be complete without me talking about my TLC BFRB worldwide family. My BFRB family expands from folks right here on Long Island just a few towns away, to Texas, California, and even further to Scotland & the UK. They come from ALL walks of life; it doesn’t matter our race, age, color, gender identity, religion, sexual orientation, or social status. They are a diverse group of

the most beautiful, unique, creative, talented humans I have ever met. I would not have met them if it weren't for bfrbs.

The factors described above reflect ideal aspects of what a Euro-American family ought to involve; trust, belonging, inclusion, acceptance, understanding, love, care. As Chapter Two mentioned, anthropological studies on kinship have often described kinship as “characterised by an unconditional amity” (Sahlins 2011: 235). Stasch (2009) has noted that this idealised notion of kinship is the reason why kinship *fails*. Taking this further, Reece has argued, “kinship is experienced, *generated, and sustained* in a continuous cycle of risk, conflict, and irresolution” (2015: 3, emphasis added). In the TLC family, with its idealised forms of care, acceptance as recovery is made possible because family are supposed to love you regardless of what you look like. This notion of recovery was clearly visible during my first TLC conference in seeing BFRB bodies revealed; with young people displaying shaved heads and going make-up free. However, as I have argued, along with others (Carsten 2000, Edwards & Strathern 2000, Reece 2015) kinship is fraught, and full of conflicts, and the TLC family is no different.

### **Conflicts of Care**

Recovery in the BFRB community is fraught and complex. While the idea of acceptance as recovery was widespread at the TLC conferences, it was often a contentious idea, particularly for family members who appear to want their children and loved ones to have total cessation of pulling or picking. At the 2018 TLC conference, I was interested in people's opinions of Milcho's keynote speech that promoted selfcrush as a way own accepting the self and living happily with a BFRB. My own view was that this idea of recovery might seem defeatist to first-time attendees. I asked Mandy and some other mothers about this later that evening in the hotel bar. Mandy said: “It's not an easy message to hear. And we see this every year, more and more parents coming and saying ‘I want to know how to fix my kid’, and they get all this acceptance talk and they think, ‘what is this shit?’” In contrast to the first-time parents, Mandy and the other

parents who have been coming for several years are accustomed to this notion of recovery, and recognise its value. They were also very clear about the importance of attending TLC conferences in order to assist with this process of recovery, which was an ongoing one for their children, who often experienced negative dips when they returned home after conferences.

Mandy and others reinforced that acceptance is not just a recovery journey for people living with BFRBs, and as my examples in Chapter Two have also shown, parents themselves have to go through a process of acceptance, in learning to let go of the suffering they experience alongside their child, and coming to terms with the idea that their child may live with this condition for most of their lives. For the parents I spoke to, part of this journey was accepting the way their children *looked*. As Mark said of his daughter Tiffany: “I’ve learned to look beyond the no eyebrows... and to see all the wonderful things that are her”. However, there are tensions surrounding this notion of recovery, and acceptance is often described in opposition to being “pull or pick-free”.

During my conversations with Beverley, it was clear that her idea of recovery from TTM was to some extent the responsibility of the individual. In a similar way to Milcho’s selfcrush project, people had to take control of their lives and want to change. For Milcho, it was about taking control of the self and accepting who you are despite hair pulling. For Beverley, it was about taking control and accepting that you could stop hair pulling, which was aided by her cosmetic treatments. However, most of the women I spoke to who attended Beverley’s expressed intense anxiety about the cost of their hair systems or extensions, and in many ways this signified how it was a “double-edged sword”. Few were accustomed to the idea that they would have a hair system for life, but instead were focused on the goal that they could overcome their hair pulling urges and one day have their own hair. Becoming pull-free was the message that the salon reinforced, despite only being achieved by a select few. In Chapter Three I mentioned the way that Beverley promoted BFRB awareness week as

“No Pulling Week”, which signified the somewhat clear-cut divide between those who consider recovery as total cessation of the behaviour, and those who feel recovery is accepting life with a BFRB and learning to live happily in spite of it. But recovery from BFRBs is not limited to either acceptance or cessation. Instead it is a process that changes over time, and often involves many different forms of care: medication, cosmetic, therapy, support groups, dietary etc, but there did seem to be a divide along these lines, and people often got very annoyed with the promotion of “pull-free” goals, like “No Pulling Week”.

In the example of Beverley’s, self-esteem is certainly improved cosmetic treatments, but it remains based on a recovery model in which the aim is to stop pulling (and to have your own hair). The financial burden of having a hair system also pressured people towards this goal, as for many the hair system was unsustainable long-term, and so they had to set themselves short-term goals in which they wanted to have it removed. While it has helped people to form relationships with Beverley herself, and her staff, attending her salon is often a solitary experience and did not involve regular interaction with other people who had trichotillomania. The “Cupcake and Cocktail TTM Nights” that I had seen advertised in the newsletter turned out to be inconsistent, and in the few years of doing my research, I was not aware of any taking place. In what follows, I will show how the acceptance model of recovery allows people to accept that recovery from BFRBs is a process, and I argue that biosocial relationships are what make this process possible. And while I argue that biosocial connections found at TLC conference bring people closer to acceptance, there are still tensions in this family that struggle to agree on notions of recovery.

From observations and interviews at the TLC conferences I showed how this organisation attempts to communicate the embodied experience of hair pulling children to parents, and encourages them to disconnect from this intersubjectivity, and to try and look beyond the visible damage hair pulling is creating in their child’s appearance. But this knowledge for parents is not always available or well-received,



and for parents in the UK without the presence of TLC, we see long-lasting effects on the recovery of and how negative care practices can reproduce isolation and shame. And yet, even for those families who *do* have access to TLC, and are present at conferences where the message of love and affection as a care practice for BFRBs is clearly sounded, this “letting go” of the personal sadness and anger that hair pulling instils in loved ones is harder to achieve.

In Chapter Two I gave examples of parents wanting to “fix” their children, and the intense emotional pain that came with this, was evident among many of the first-time attendee families at TLC conferences. I raised this topic with parents who had been attending the conference for several years, and they confirmed this dilemma. Mandy said, “I see it every year, parents come looking for ways to fix their child. But then you don’t find that”. The Maxwell family reiterated the same point, and during a conversation with Tiffany’s parents, her mother Penny said, “We learn new things every year, but it’s mostly for her now. We’re not coming for us anymore”. When I asked how this compared to their first conference, Mark said, “You come looking for answers. You get help and *support*, but you don’t get answers” (Mark’s emphasis).

For the parents I interviewed, TLC conferences helped them to overcome this need to “fix” their child. At the conference sessions, parents are taught that BFRBs are more than just the physical effects, that they are complex embodied disorders that require multiple forms of care. Parents are encouraged to find sensitive methods of drawing attention to hair pulling or skin picking that will not make their child feel embarrassed or ashamed. Through the accounts presented here, we see how different families deal with hair pulling children, learning new ways of caring for their children. It is clear that TLC is a valuable resource for many American families, their attitudes towards care for children with BFRBs requires parents to stop being overly concerned with the visible effects of BFRBs, and to consider the complexities of their child’s experience that requires a multi-faceted approach to care. As I have shown, since parents experience a shared suffering with their children, I argue that the idea of acceptance as recovery

creates conflict because it highlights the limits of intersubjectivity between parents and children, and ultimately their lack of control over their child's behaviour.

This challenge was clearly visible to me during the first session in April 2018. A grandmother had come to hear about recovery. After a while of listening to people talk about "acceptance" and ways of coping long-term with their BFRB, she raised her hand and shouted out: "But if you're sitting next to your granddaughter who won't stop pulling, what do you *do*? I don't know what to say. I don't know what to *do*". The group responded thoughtfully, and for most of the remaining time, people added their thoughts to help the grandmother, offering suggestions on how to help. Some of the advice was "Take her hand gently, don't draw attention to the pulling" - "Ask her what *she needs* rather than assuming you *know* what she needs" - "Tell her you love her". Later that morning I bumped into the organiser, Pam, and thanked her for the workshop. She told me she wasn't sure how well it had gone, and said that the grandmother had approached her after the session and said she hadn't found it useful. This surprised me, and I reassured Pam that I thought people had really tried to offer their help. Pam shook her head and said, "I understand, you know, she just wants to find the answer that will make her granddaughter stop. But she won't find the answer here".

Here, the grandmother is explicitly told by other people living with BFRBs what her granddaughter needs, and this includes being told she is loved. As I have shown earlier in this chapter, love and belonging are important aspects of the TLC family, as they are often considered to be missing from families at home who lack the complete embodied understanding of the biosocial community. The feeling of shared understanding goes beyond the sufferers themselves, and parents of BFRB children also feel the support of this family as they are able to meet one another and build strong bonds between one another. So membership to this family not only includes people living with BFRBs, but extends to their own families who attend the conference with them. Interestingly, it also includes some of the clinicians and professionals who

have been part of TLC's journey, in particular those who teamed up with Christina Pearson in the early years, whom they called "the mother of TLC". At the Dallas conference in 2016, I spoke with numerous clinicians and several of them referred to the community as "like one big family." For them, there is something unique about TLC, as one clinician told us: "There are other organizations that serve sufferers and professionals, TLC is not the only one. But none have so successfully merged, and this one is very special, almost every professional that has become involved with it feels that special connection between the consumers and the professionals, that there's less of a divide, that people feel very comfortable." But Beverley's salon, for example, was not considered a family, despite the obvious benefits of sociality described here, and the explicit mention of "love". As I have shown, while clients felt comfortable in the salon, and were able to improve self-esteem, the cost of attending became a cause for concern. In many ways, Beverley's salon is not perceived to be a family in the same way, is due to the awkward relationship between money and care, as care is complex when money is exchanged. Although based on idealised notions of kinship, the TLC family is not immune to the conflicts of care tied up in economic pressures, and while people certainly *valued* the conference highly, the cost of attending was mentioned frequently, and for many acted as a barrier to being with their re-connecting each year. TLC is focused on money in increasing ways, and their role as a non-profit organisation is tied into their identity as a family. On the one hand they are based on imagined ideals of kinship, but on the other they require money in order to sustain this community.

### Care or Cure?

As I have shown above, the power of the TLC conference in allowing people to achieve acceptance, and the longing for people to be reunited, means that annual attendance at it each year becomes increasingly important. In her notion of the circles of care Lesshaft (2016) has argued that practices of care establish both "connection *and* separation, intimacy *and* distance" (Lesshaft 2016: 6). In a similar way I argue that

biosociality makes self-care possible, connecting people intimately while also reminding them of their distances when they return home. But despite this intimacy, the power of these spaces to produce effective forms of recovery, and the bond created in these spaces, connects people even after the weekend has ended. Despite living in London, Dhaya's dependence on the TLC family is strong, and in April 2018 when she was almost unable to attend due to the financial strain of the conference, it reinforced some of the issues with the conference accessibility. When discussing the importance of the TLC family to people's recovery, Mandy mentioned Dhaya as an example, and said, "The fact that Dhaya almost couldn't be here at such an important time in her journey, I was saying [to TLC], how do we get the people here that *need to be here*? Because this is so unachievable for so many people, just [cost of] the flight alone" (Mandy's emphasis). For Mandy, TLC's inaccessibility is because the conference not being officially recognised as a form of treatment. For her, if these events were valued in terms of recovery, then this might lead to them being recognised on health insurance, allowing more people to be able to attend. The financial pressure on families to attend conferences each year in order to support their loved ones is an important issue, and raises questions about the sustainability of organisations like TLC. Clearly regular funding is needed to make these conferences possible, and regular funding appears to be based on alternative notions of recovery linked to pharmaceutical intervention.

It is this tension that appeared to trigger the need for TLC to re-brand in 2016. The 2016 Dallas conference for TLC was significant for two reasons; firstly, it marked their 25<sup>th</sup> Anniversary as an organisation, and secondly it was the year that they had an identity change, from the "Trichotillomania Learning Center" to "The TLC Foundation for Body-Focused Repetitive Behaviors". The name change was important for the future of TLC as they embraced the inclusion of other disorders, such as skin picking and nail biting. Alongside the change in name, they also updated their business tagline which moved from "Together we are Stronger" to "Sharing Knowledge. Supporting

Recovery. Finding a Cure”. The logo also changed from a symbol of a person with open arms (Figure 18), to a square box with gap in it (Figure 19).



Figure 18: TLC Logo 1993-2016

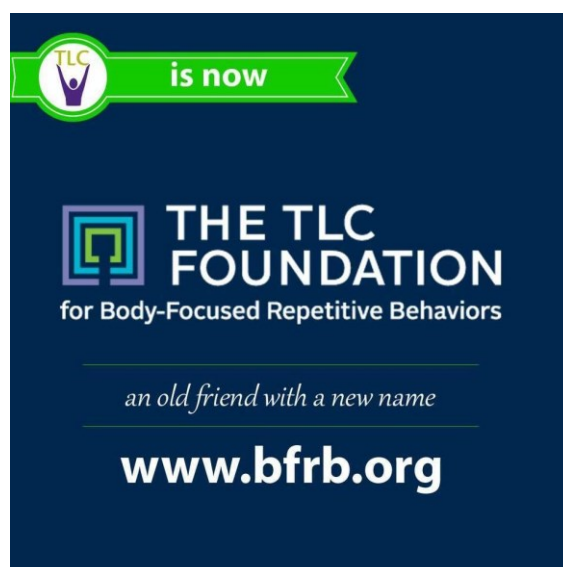


Figure 19: TLC Logo from 2016

Dhaya and I discussed this change in March 2016. I was staying at her home in London and we were planning our upcoming support group meeting when I received the email from TLC announcing their new name. We looked through the new website together. Surprised at the changes, Dhaya commented that it looked much more “clinical” and “scientific”. She thought that this must be to gain the attention of the medical world and to try and attract pharmaceutical funding. But the “cure” language marked a clear

change from the ethos of the organisation, which had previously focused on community care, towards a more professional organisation specialising in medical cures. I asked Dhaya, “If they found a cure today, then would people still come to the support group on Sunday?” She burst out laughing and said, “Of course! Because people give up drinking but they still need to go to AA!”

I was intrigued by this change, and continued these conversations with my American informants at the conference the following month in Dallas. Troubled by the idea of a “cure” I asked people if they were looking for a cure for their BFRB? They all said they were not. Their reasons were due to the social experiences that living with compulsive hair pulling or skin picking had brought them; most important of all, was the community that surrounded them there at that conference. Zara said: “I wouldn’t have met all of these amazing people! And I wouldn’t have learned so much about who I am”. I talked to a couple who had met at a TLC conference several years ago. They both had trichotillomania, and had since fallen in love and gotten married. They were certain they wouldn’t take away their BFRB as it was the one thing that had brought them together. I left the conference that year quite surprised by these comments, but I began to notice similar statements in social media posts following the conference. Quite literally, while sitting at Dallas airport waiting to fly home, I saw a post by a young woman who reconfirmed this message:

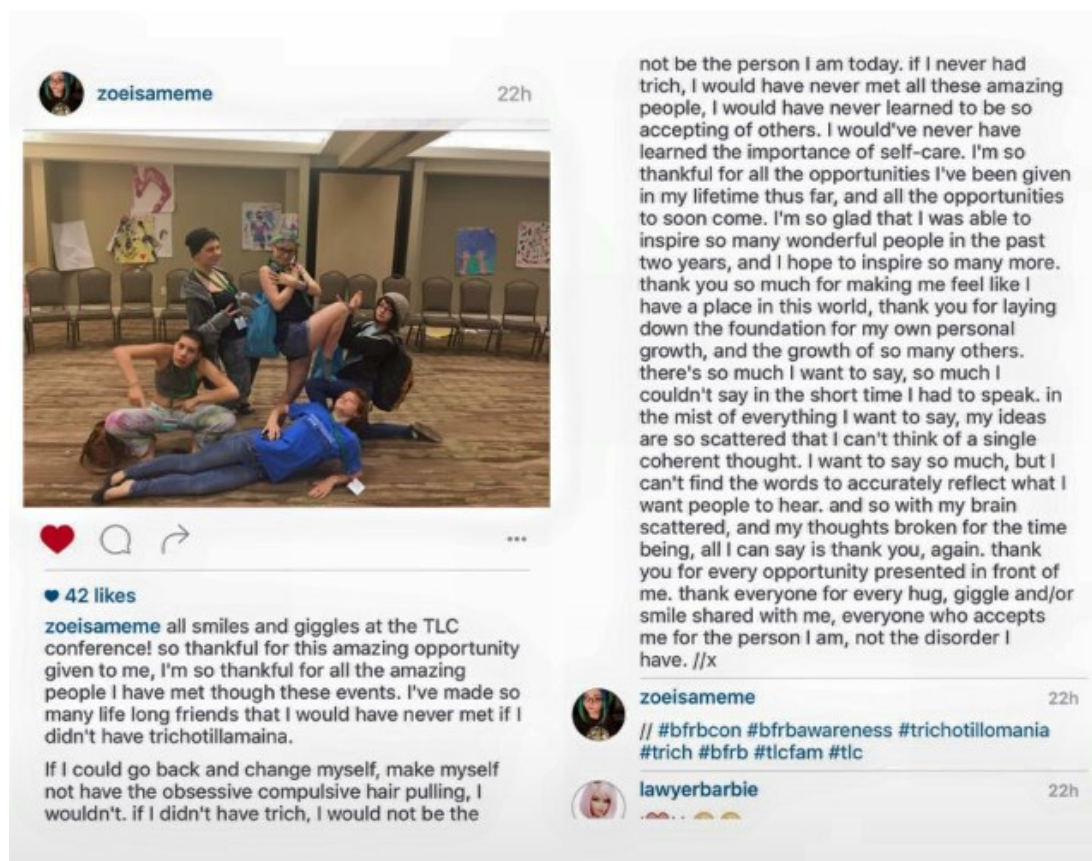


Figure 20: Zoe's Instagram post, April 2016

The change in TLC's name and general ethos of the organisation, felt fraught at the conference that year, and there was visible tension between Christina Pearson and other staff and board members on the stage during the closing speeches. Christina was invited up to present the winner of the annual Christina Pearson Award for exceptional service. Before doing so, she read an extremely long poem and then took her time to give an overview of her journey as TLC's founder:

It has been such an honour to be a channel for the birth of TLC, I am a mother, I have none of my own children, but you are *all* my children. And I wrote that poem I wrote because I have no other way to express the *yearning* of that love in me that wanted to touch the love in you... You know I walked away from a life, I walked away from a job, I walked away from a company I owned, and I walked away from owning a house, and moved into a ten-by-twelve cabin with no indoor plumbing to give birth to TLC. It's nice to see [pause] it grew up! [Christina's emphasis].

After much applause, the Board and staff standing behind her in a line, smiling, she went on,

But the lifeblood of TLC is not the Board, it's not the staff, it is *us* as a community, it is us as sharing a non-verbal understanding of the difficulties and sufferings that we struggle with... and it is us as individuals that can change the world, I know because I've done it. We *do not want to wait* until we get well to start living! [More applause]. In the early years of TLC, we created two events: the conference and the retreat. The conference is the necessary invitation into the science and the validity of these arenas. The retreat is more the heart of the work which is transformational and experiential. [At this point the staff and Board members behind Christina started to shuffle, moving their feet slightly, they looked uncomfortable, but she carried on unaware]. But *both* are incredibly important, y'know? You need your mind and you need your heart [Christina's emphasis].

Christina finally went on to introduce the winner of the award, Babby, and described when they met at an early retreat. She told us that after that weekend, Babby went back to New York and started a support group, and wrote news articles to raise awareness. Of this work, Christina said, "And she did all of this, from nothing more than a desire to *connect*, with us. The heart draws the heart, and it can help heal the heart". Christina's long speech, and all that it contained, was incredibly telling of TLC's wider situation. Others felt it too, and spoke afterwards of the tension and awkwardness. The general view was that TLC needed an identity change in order to be taken more seriously, and people believed that Christina might not fit within this image. Whether or not this was true, when I returned to the 2018 conference, Christina appeared to have less of a role. The story of Christina shows the ways that families can be fraught, full of risk and tension, and the TLC family is no different. Made up of a complex catalogue of people, including staff, clinicians and researchers, the future of TLC and the sustainability of the community is uncertain. The constant request for fundraising reminded everyone at the conference how fragile the situation is, and reinforced the view that the organisation may be searching for funding from Big Pharma.



But despite the tensions, the talk of “family” and “love” from TLC was stronger than ever that year, and was embraced fully by the Chair of the Board when he gave his speech at the fundraising dinner to describe the recent research agenda: the BFRB precision medicine initiative (BPM). He said: “we’re doing this because we care and we love this community... BPM had to come from us, we couldn’t rely on anyone else”. What he means, is that the funding from BPM had to come from the community, but it seemed that this was the only option as numerous attempts to gain external funding had previously failed. The support for TLC from the community is strong in this sense, and the organisation depends solely on financial contributions from “the family”.

The TLC family is in many ways built on idealised framework of kinship, but as we have seen, kinship is not without conflict. Challenging the notion of nuclear families among gay and lesbian people in America, Weston (1991) argues that we need to, “examine historical transformations in kinship, ideology, and social relations – transformations that could not have come about without conflict, contradictions, difference and struggle” (1991: 7). Care, as I have argued, is far from harmonious. In Chapter Two we saw how parents struggle to care in obviously “loving” ways for their children, and this perceived lack of love is often what strengthens bonds to others in the biosocial group. Like Dhaya, for example, who felt that compassion was missing from her childhood, and so the love from the TLC family has allowed her to practice self-care and find compassion for herself. But it is not to say that love is either missing or present, but that care in families is complex and is not without tension or struggle. The TLC family is further complicated due to its double-identity as both a family and a non-profit organisation, and care often becomes more complicated when financial obligations are involved. Reece (2015) has critiqued the way the NGOs in Botswana have adopted the framework of kinship in their HIV/AIDS care services. She notes that NGOs, unlike Tswana families, fail to see kinship’s “creative potential of conflict and crisis” (2015: 4). The difference in the care provided by NGOs and the care provided by families is not only determined by money. If we only consider the financial basis of this care, then we likely fall into the assumption that paid care is not “real care”. Street (2016)

debates the idea that one cannot care *for* a person without first caring *about* that person. She says, “This understanding of care is premised on an old opposition between self-interest and altruistic compassion that leads inevitably to the impression that professional care is morally compromised” (Street 2016: 333). In many ways, TLC is not an ordinary organisation. Despite the sense of financial obligation from the community towards TLC’s sustainability, love is not diminished through this transaction. There is an important difference here between the money exchanged within the TLC community (paying to attend conferences is expensive), and the financial burden experienced at Beverley’s salon. The difference is what makes TLC a family; a family that acknowledges conflict and crisis alongside loving care. Using the words of Heinemann (2014), TLC is a family that people can “rely on, who offer emotional and material support, who share a past, and whose ties are resilient even in the face of conflict” (2014: 70).

## Conclusion

This chapter has shown how recovering from BFRBs is complex process. Here I have focused on the difference between acceptance and cessation strategies as this difference creates opposing views in the community. Recovery is an ongoing process, made up of coping mechanisms and techniques that people learn for themselves throughout their lives. When considering self-care, I argue that self-esteem and self-care are connected in important ways; that self-care is harder to practice for people with low self-esteem, and also that self-care is deeply relational. Through biosocial communities, people can improve self-esteem, which influences their ability to practice self-care. Self-esteem was enhanced by cosmetic treatments, but these treatments were based on an alternative model of recovery that reinforced the anxiety of living with hair pulling. For many people, recovery involved elements of accepting the visible self, but also accepting the presence of a disorder that may not be curable. Acceptance was related to living life, and not allowing BFRBs to prevent people from doing things they enjoy. Acceptance means people can accept how the self looks.

Milcho's selfcrush project shows how challenging this task can be, but shows how people attempted to find self-compassion, and how self-care was a relational process. But the acceptance model of recovery was something that families also to come to terms with; and many were unable to do this.

I illustrated the way that the TLC conference creates an intimate environment that people identify in terms of kin relationships. Through these bonds with a wide range of people connected to BFRBs (in both personal and professional experiences) people are able to find new ways of understanding and coping with their behaviour. The love within the TLC family builds on this idea, and I have argued that through compassion for one another, people are better able to feel compassion for the self. In turn, increased self-esteem found through self-compassion leads people towards self-care practices. I argue that self-care is a relational process that can be strengthened, made more meaningful and more effective as a form of care, through the support of others. This can be seen in visible transformations of the TLC conferences, and shows how people alter their view of themselves through the realisation that they are not alone, and through entering into the love and support of the TLC family. However, I have also described how certain tensions within this family exist, made evident through apparent divides in notions of recovery. Ultimately, I argued that TLC is a family in which love and conflict sit side by side.

The fact that TLC has set their goals on scientific research that will uncover a cure for BFRBs is perhaps a result of pressure from the Board of Directors, the Scientific Advisory Board, or by parents. The reasons why this change occurred are not entirely relevant, but there are implications for the future of the organisation, as well as the people it serves. While Christina Pearson insisted that the lifeblood of TLC is the community itself, and gave little value to the scientific contributions; the sustainability of the organisation depends on their work. TLC has helped to make BFRBs visible across the globe, which in turn has shaped the way that people are able to find one

another and build biosocial bonds. And so, visibility, care and biosociality are interlinked, and this ultimately gives rise to conflict, risk, and precarious futures.



## Conclusion

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### **“We need to make *noise!*”**

It was April 2016, and the last morning of the TLC conference in Dallas. Emotions ran high. I looked around at the adults and children hugging, faces full of smiles and tears, anticipating their goodbyes. A small group of us found a table close to the stage, sitting tightly together. We chatted anxiously, until Jennifer, the Executive Director, took to the stage and smiled widely at the room in front of her. Her voice was shaky, “How are you all feeling?” The audience cheered and whooped loudly. “We’re going to get started with a very special moment, in a moment we’re going to announce the results from last night’s fundraising dinner, but I want to tell you that I am so touched, so *personally* touched by the outpouring of support from this community, thank you all”. The donations given from attendees the night before had totalled \$31,000, which along with further donations from the Board of Directors made the total money raised in one evening \$81,500. The announcement caused several gasps from the audience, who got to their feet and applauded. The message was clear: if there was any risk that that this organisation may not be able to continue its work, then the community cares. They want to support the future work of the world’s only organisation working to find a cure for body-focused repetitive behaviours.

The previous evening Jennifer had given her speech at the end of the conference’s fundraising dinner. After much applause, she began to speak:

I recently sat down with a billionaire. Yes, I was surprised to find myself sitting on his enormous white leather couch, but a TLC member had generously arranged our meeting. I told the philanthropist about TLC and our community, and I asked him for \$2 million to support BFRB research. After our team had concluded our presentation, the philanthropist looked me in the eye and said: ‘You need to do your job better. This is not *my* cause. Where are *your* people?’ I was incredulous. What did he mean, *my people*? The greatest thing about this organisation is its amazing, inspiring, dedicated people. [The audience whooped and cheered for a moment, then she continued] He reminded me of the autism community, and when

the parents began their movement. He said, 'You could not *shut those mothers up*'. And I realised, he was right. [She paused] We need to make *noise!* [Jennifer's emphasis].

The audience cheered and clapped loudly in accordance. Jennifer went on to remind us how far TLC has come in the twenty-five years since it began, and how the tenacity of its founder Christina Pearson helped to put trichotillomania on the agenda for researchers in the United States. But since then, they have relied solely on donations from the community, and the continued interest of their Scientific Advisory Board to support research and further knowledge into possible treatments for hair pulling and skin picking. Jennifer thanked the audience for their dedication, and noted that without their membership and donations, TLC could not continue the work that they do. She brought our attention to the donation cards on the tables, and asked us to give whatever we could. She said that in order to show the world how much this community cares about the future of BFRBs, the Board of Directors would match every donation that is made. The audience clapped and cheered again, as she left the stage.

Sitting to my left I watched Jack write a cheque for \$1,000. He smiled at me as he signed along the dotted line, shrugged his shoulders and said "business has been good this year". To my right was Christine, a woman in recovery from compulsive skin picking. She was with her three month-old baby, and as she stared blankly at the donation card, she explained to me that she was waiting for money to come in, and wished she could give something. I too admitted my guilt at not being able to donate, keenly aware of the debt my fieldwork had already accrued and the financial efforts it had taken me to get to the conference that year. But then Christine said, thinking aloud, "But if I don't give today then my donation won't be matched by the Board." She pondered for a moment, and then reached into her bag to pull out her credit card and scribbled down her donation. I sat there quietly for a moment, and then I joined them - filling in my own donation card for \$100.

There was a sense of urgency in Jennifer's call that evening, which sat alongside the tense atmosphere of the 2016 conference. It was the same year that TLC changed its name, from the "Trichotillomania Learning Center", to the "TLC Foundation for Body-Focused Repetitive Behaviours". As I mentioned in Chapter Five, this identity shift reflected a potential change in the focus of the organisation for the future, and its sustainability was clearly being called into question. The concern over long-term funding was well-known, and had been mentioned in various conversations to me over the weekend. TLC's new image as an organisation was speculated upon as an attempt to attract private investors from outside the community; their new logo apparently necessary to appear more "professional" and "scientific". 2016 was also significant as this was the year that the Scientific Advisory Board revealed their plans for the upcoming BFRB Precision Medicine Initiative (what they called BPM). BPM has an ambitious goal of reaching 70% remission rates for 700+ participants within 7 years. The research project aims to determine the biological and genetic patterns for individuals with BFRBs, and then go on to tailor personalised treatment plans to each person. The overall funding requirements were \$2.8 million, 90% of which had apparently been reached by the time of writing this thesis. But at the 2016 conference, the push for funding BPM was strong, and as I sat in on research sessions I heard convincing arguments about the role of biomarkers and the importance of genetics. The Chair of the Board gave a brief history of BFRB research:

The history of research at TLC has been these good people doing the work really in a boot-strapped way, and often just funding it out of their own pocket or their own time, their own good will because they care about us. And as a Board we decided we need to do more. Now, there has been some money donated over the years, but we felt like we needed to do more... Look where we have come in three years, because we took a chance to try and do more, we always had the wonderful researchers, we always had them. But as an organisation we needed to try and do more and I'm really, really amazed... imagine where we'll be in three years. This is really exciting.

Throughout the research talks I heard about aims for "total cessation" of pulling behaviour, which one researcher said was "obviously what we want to achieve".



Alongside these goals, it appeared that anything less was considered a failure. And yet what this thesis has shown, is that total cessation was rarely the goal for people I spoke to. Overcoming BFRBs may have been the focus of research discussions at the conferences, but the most meaningful element of these weekends for people with BFRBs was the sociality, and the feeling of acceptance within the TLC family.

So what does the BFRB Precision Medicine Initiative mean for the BFRB community? This research agenda highlights the disparity between scientists researching BFRBs, and people looking for coping mechanisms in everyday life. It also reveals the vulnerability of mental health funding and the scramble for money from year to year at TLC conferences. The funding plea for BPM reflects a desire for BFRBs to become visible and recognised as mental health conditions worthy of support and research, which is measured in terms of financial support. But BPM is also a push towards more treatments that are tailored to the *individual*. However, I have demonstrated the ways that individual care is intimately linked to collective care. How effective will a precision medicine initiative be if it does not also take into consideration the value of social networks of support? And if TLC are successful in finding a cure for BFRBs through BPM research, what does a community do with this information? What will future scientists and medical professionals do when they find biomarkers that show someone is at risk of a BFRB? These questions cannot yet be answered, but they highlight an interesting shift in BFRB consciousness, and the importance of this thesis in the wake of things to come.

## Thesis Overview

My thesis began by laying out the individual, embodied experiences of living with BFRBs. Chapter One described the ways in which people with these behaviours hide, using various techniques of concealment, covering hair loss and scars in order to keep their BFRB a secret. I demonstrated how techniques of concealment become essential to daily life, but that they also change over time; influencing life course expectations,

and triggering different feelings of acceptance after years of hiding. The process of hiding was considered arduous and difficult to maintain, often causing people to avoid social situations where the BFRB body may be revealed. I examined the fear and risk of revealing the BFRB body in relation to social stigma and internalised shame. But we saw that the visible effects are just one element of what it means to suffer from BFRBs and I revealed the importance of embodiment. By looking more deeply into experiences of body, mind and self, we saw the complexities of these behaviours and how regular intense urges and confusing sensory rewards create mixed reactions, combining pleasure and disgust, satisfaction and guilt, care and harm.

Chapter Two developed the theme of stigma, describing the challenges that people faced in communicating their BFRB experiences to loved ones and family members. Through my conversations with parents, it became clear that kinship can be understood as a mutuality of being, where parents and children share intersubjective experiences of loss, sadness and frustration. I argue that because families are bound intersubjectively, parents' descriptions of feeling "powerless" demonstrates that mutuality of being has limits. We saw that the lack of complete understanding from close kin often led to cruel remarks, physical punishment and embarrassing comments. These reactions had the potential to reinforce the isolation, confusion and shame of having a BFRB that people already experienced. Acknowledging that kinship is not always harmonious and obviously loving, I argued that these responses are in fact care practices that involve elements of love and harm. Building on idealised notions of kinship, I explored people's expectations of the role of a mother, showing how memories of harsh mothers had long-lasting effects on women, often extending into the next generation of daughters, reminding people of the embodied risks of their disorder. We began to see how care in the BFRB community is reproduced, and how experiences of care in families can cause people to reflect on their own self-care practices.

In Chapter Three, we saw the way that BFRBs are viewed in public culture. I argued that the current media coverage of BFRBs in the UK press has shaped the visibility of these disorders and in ways that excludes men and people of colour. I described how this visibility is influenced by Beverley, and that the promotion of her treatments reinforces the notion of hair as a commodity, brings both opportunities for empowerment and risk. I argued that the hyper-visibility of the “white female TTM sufferer” enhanced by Beverley through the press, has the potential to negatively influence help-seeking behaviour other people with BFRBs. The images of these women in the media also pertains to the idea that hair loss ought to be covered, and feeds into gendered stereotypes relating to beauty norms, ultimately reinforcing the shame connected to BFRBs. Despite these dominant spectacles in the media, we saw examples of women who have been resisting these cultural beauty norms; working to change the way they are represented in the public eye.

In Chapter Four, I described the process of finding and forming a biosocial community. Stemming from the moment of diagnosis or finding out “the name”, people were suddenly changed by the information that their “unusual” behaviour was had a medical label. We saw that the realisation of their shared experience with fellow sufferers became meaningful. In this chapter, I explained the way that biosociality changes aspects of individual identity, allowing people to feel better about their behaviour, bringing a sense of normalcy. However, diagnosis also led to disappointment, as it rarely led to treatment options or professional care. I highlighted this irony of medicalisation theories and showed how self-care flourished in the absence of medical care. Importantly, we saw how caring for the self is strengthened by the biosocial group, through collective self-care. And yet, it was clear that the journey to biosociality has challenges, involves risks and is, in many ways, exclusive. Acknowledging the limits to biosociality, I proposed the concept of biosolidarity in order to account for the way that people feel compelled to *do something* with their new label. Through acts of biosolidarity we saw how people actively shape the visibility of their conditions, and simultaneously create opportunities for the community to

grow and strengthen. The circle of biosolidarity illustrated how biosociality and biosolidarity work in circularity with one another; increasing the recognition of BFRBs while at the same time increasing the likelihood that people will find the community sooner. Through this process of making BFRBs visible, people themselves come into view, and these acts of biosolidarity challenge the existing media coverage of BFRBs, reshaping the way that the world understands and views these conditions.

In my final Chapter, I drew together the various elements of this thesis and showed how biosocial networks have the potential to shape notions of recovery. I described the meaningful relationships formed at TLC conferences, and the way that this community was referred to as a family. This family was understood to be based on care and love, and was especially important for people who felt that these aspects were missing from their childhoods. The importance of love that comes from the community, had a direct effect on the self, and in this chapter I argued that love in the TLC family forms the basis of collective self-care, which makes individual self-care possible. I argued that through circles of care we can see how self-care is deeply relational; linked to perceptions of the self which are reflected in others. Through the TLC family, individuals are able to improve their low self-esteem, practicing self-compassion and acceptance. One way of doing this is through various technologies of care, like mirrors and photographs, which quite literally seek to change the way people see themselves. I argued that the TLC family is based on idealised notions of kinship, and connecting to my argument from Chapter Two, I showed how this family inherently involves conflict and harm. We saw how tensions arose around notions of recovery, and began to get a sense of the financial obligations that are involved in this family. And yet, the acknowledgement that families are based on difference, conflict and harm as well as relatedness, love and care allows us to see the overriding value that this biosocial community offers people living with BFRBs.

## Acts of Biosolidarity: Measuring Impact

My thesis has followed the emergence of the BFRB community. Through the narratives of my interlocutors, I have tried to capture the multiplicity and diversity of BFRB experiences. I have shown the ways that men and women work to conceal their BFRB bodies; the stigma and shame that influences their techniques of concealment; while at the same time disentangling the meanings, emotions and relations that are revealed by this secrecy. I have critically examined the factors that shape these experiences of stigma, highlighting the gendered and racialised norms that influence experiences of these behaviours as well as the power dynamics that determine who is made visible in public culture. As I followed the process of diagnosis I argued that medicalisation both enables and limits people's abilities to care for their BFRBs, showing how medical diagnosis can lead to social networks of care that contradict biomedical frameworks of care. The crux of this thesis has shown the great potential of biosociality to create alternative notions of recovery. I have argued that biosociality is a form of kinship, and that biosocial groups can become intimate families that assist in the process of caring for each other. But I have also argued that kinship itself, is inherently fraught and full of vulnerability and tension, often burdened by the responsibilities of duty, money and care. I argue that biosociality also includes these conflicts and frustrations; it is incredibly fragile, and completely dependent on people working together to keep it sustained. I have proposed the idea that biosociality can lead to acts of biosolidarity, where both the limits and the potentials of biosociality can become productive avenues for awareness. The circle of biosolidarity that I present in this thesis captures the relationality of these acts, as well as their ability to reproduce these important community networks. Coming full circle, I have argued that through the intimate bonds of BFRB relatedness found in biosociality and performed through biosolidarity, many of my interlocutors have been able to alter the way that BFRBs are viewed, and thus the visibility of a community emerges hand-in-hand with those who advocate on its behalf. I include myself in those people, as this thesis is clearly an act of biosolidarity. My view into the world of BFRBs is pioneering, and creates important

links between anthropology, psychiatry and the lay people who live with these disorders. This research not only broadens our understanding of biosociality, kinship relations and the lived experiences of mental disorders, it presents BFRB voices in a way that current research has failed to do. And as we have seen - this community wants to be heard.

The process of doing social research is a deeply personal experience in many ways, as we ask others to share their lives with us. What our communities choose to express is largely influenced by who we are; our positionality shapes our ability to conduct research and the direction it takes. This is especially true for ethnographic work which demands a longer process of intimacy and greater intensity with our chosen community. Throughout this research journey, my own positionality both daunted and liberated me; methodologically and emotionally. My position as a self-declared long-term sufferer of BFRBs acted as a way in to an otherwise very private community, and shaped the deep relationships that I went on to form with my interlocutors. It also felt like a huge burden at times, weighing me down in terms of my sense of obligation to others. The community that I describe in this thesis, appears at times to be singular, unified despite being dispersed across the globe, online, coming together in conferences and support groups. In the UK, the picture looks quite different, and through the process of conducting this research I often felt as if I was the only person supporting people with BFRBs. By adding my email address and phone number to the only UK support website for trichotillomania, I was putting myself out there as an “expert” for people to contact. One day in the midst of my fieldwork, I received a telephone call from a worried mother, who had urgent questions about her young daughter who had pulled out most of her hair. While receiving emails and calls from people was common at that stage, this was different, as the mother explained to me that she had spent the last hour calling various helplines; Mind, The Samaritans, OCD Action, and others. She told me she had called eight different helplines, and after not one call being answered, finally she got through to me.

After our half an hour phone call, and the wide range of advice I was able to give her about hair pulling tactics for children, I wondered how much information she would have been given had she got through to any of those organisations before me. The reality then, and now, is that there are very few people who know much about BFRBs, and even fewer who are able to support the many people out there struggling with these behaviours on a daily basis. I have felt the weight of this responsibility throughout this project, which very quickly moved beyond the scope of the PhD research alone. This was the main reason I chose to set up support groups in the locations I was travelling to regularly. Being able to work closely with other people across the UK to try and improve the support options available for people living with BFRBs has been hugely rewarding, and has shaped my understanding of the value that these support networks have. The power of these relationships is central to my argument; people are able to find a sense of recovery through the collective care from one another. Through the process of building these relationships, a community becomes visible, and through increased visibility comes improved awareness and better information. But while I have argued for these support networks to be recognised as legitimate and efficacious forms of care, the role of collective care is called into question with the drive towards precision medicine initiatives, and the potential for pharmaceutical interventions hoping to eradicate BFRBs in future generations. In this thesis I have attempted to make the BFRB community visible, but I am aware that bringing this community to the attention of an academic audience is not enough. The impact of this work on my own personal life has been profound, and is down to the people with whom I have worked. But my contribution to this community is dependent on the continuation of these social ties, of recognising the value in communities that care for one another through experiences of stigma and isolation. While this thesis hopes to speak to themes important to intellectuals, I believe the real impact of this work is felt in the groups I continue to work with; in the relationships that we have formed together; and the potential of our advocacy work to make BFRBs better seen, heard and understood in the future.

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